HCC
South East London and South East

South Thames Sickle Cell & Thalassaemia Network

Issue 17

RedCell Newsletter

Welcome to the latest edition of Red Cell News Issue 17.

Despite the challenges of 2021, there have still been many positive developments across the South East London and South East region. Across our clinical network, there have been various educational events which provide staff from a wide range of clinical backgrounds and representing different hospitals with the opportunity to gain further insight into sickle cell, thalassaemia and rare anaemias. Our local support groups have continued to meet virtually on a monthly basis to keep patients informed about the latest topics of interest and also hopefully to provide an informal opportunity to meet with other patients and staff. There have been a number of new and ongoing developments regarding new treatments (including Bone Marrow Transplants and novel treatments — eg: Crizanlizumab, which is featured in this issue).

Our key educational events over the past six months, have been to host two Royal College of Nursing accredited Sickle Cell & Thalassaemia training days. We also enjoyed our first ever virtual Patient Sickle Cell Awareness Day, in July 2021, which was a huge success and was very well attended with over 100 patients and staff members joining us virtually.

We are also very pleased to welcome new staff members to our network and we look forward to working alongside them in the future. Read on to learn a little more about some of our teams.

We continue to update our website to include information for patients and clinicians, please take a look at www.ststn.co.uk. We're always looking at new ways to improve our to make it our resources as useful as possible for patients and professionals alike.

We wish you all a Happy Christmas & Happy New Year!

In This Issue:

Mission Statement:

"to improve patient experience by offering better treatment outcomes for people with sickle cell and thalassaemia"

Visit **patient zone** on our website: **www.ststn.co.uk** to find patient information, clinic times, support group information and previous editions of the red cell newsletters.

KING'S HEALTH PARTNERS

Pioneering better health for all

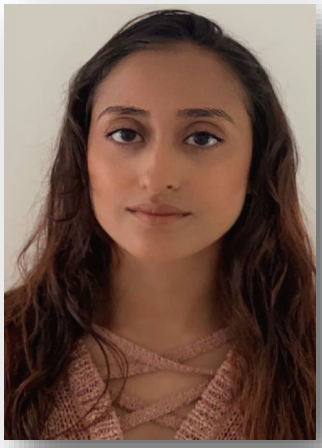
New Team Members

Dr Arne de Kreuk, Adult Heamatology Consultant

I joined the adult Red Cell Team at King's College Hospital as a consultant haematologist in August 2021. I will work alongside Dr Moji Awogbade and Dr Sara Stuart-Smith in outpatient clinics and on the wards at Denmark Hill. We are at the dawn of a new era of treatment options for red cell disorders. We now have bone marrow transplantation available for adult SCD patients and crizanlizumab as an alternative option for prevention of sickle cell pain will be introduced shortly. New disease-modifying drugs both for sickle cell disorder and thalassaemia are on the horizon. I look forward to meeting you in clinic or on the wards and help support your health as well as talking about what the new treatments may have to offer you.

Shaira Chowdhury, specialist Nurse Case Manager within Sickle Cell & Thalassaemia community services.

I support Adult patients with sickle cell and thalassaemia within the community. The centre is based at Wooden Spoon House but I attend clinics at least once a week as well as the obstetric clinic at the end of the month. We offer a variety of things such as antenatal testing, genetic counselling, welfare support and chronic-disease management support – the list goes on. I worked for Barts Health Trust previously but I am now working for Guys and St Thomas Trust



Rachel Davidson, Haematology Social Worker

Rachel has been part of the team since October 2021; she previously worked part-time in the haemato-oncology team for 1 year, and now has a full-time role that covers the whole haematology service. Rachel brings with her experience of working with the haematology team, and connections with community services in order to support patient's social and practical needs

Prior to working at King's, Rachel worked in Children's Services in a Local Authority; she has extensive knowledge of protection and safeguarding for children and adults, and working with individuals experiencing adversity or discrimination. She has a particular interest in supporting young adults to transition through services.

Rachel has considerable experience in advising on housing, finances/benefits and immigration issues. She is motivated to bring this knowledge and experience in order to improve outcomes, and increase support, for patients with sickle cell and thalassaemia.

Dr John Brewin, Paediatric Haematology Consultant

Has recently joined the paediatric red cell team at Kings College Hospital as a new consultant. For the last six months, he has been working in the adult red cell team here, and thoroughly enjoyed his experience. However, he is delighted to be back looking after the children he has got to know during his time as a research clinician. His PhD investigated stroke complications in children and adults with sickle cell disorder. He learnt a great deal, and hopes to continue to investigate causes of this important complication of sickle in his new role, whilst ensuring our children receive the best possible care. With many new treatment options finally starting to enter our clinical practice, we have the opportunity to offer therapies more tailored to individual patient needs. He looks forward to meeting you in clinic and discussing the best available treatment options for you and your child

Sabah Mahmood, Practice Development Nurse for the South East of London & South East HCC.

I joined the Haemoglobinopathy Coordinating Centre in August 2021. I qualified as a nurse 10 years ago from King's College London. I initially worked in general medicine and paediatric ambulatory care.

I have worked for the last 5 years as a Clinical Nurse Specialist in Paediatric Haemoglobinopathies at Kings College Hospital.

I will be working alongside the HCC team in facilitating teaching and nurse education across the centres to improve and maintain safe, evidence based and high quality care for patients with sickle cell disease and thalassaemia.

I am passionate about these patients and am a strong advocate when it comes to their health and wellbeing. I am looking forward to getting stuck in to this role with the aim to improve patient outcomes.

Dr Joanna Adebayo, Clinical Psychologist at Lewisham and Greenwich NHS Trust,

My role is to support children and young people with sickle cell disease and thalassemia and their families or carers.

I obtained my Doctorate in Clinical Psychology at the Salomons Institute for Applied Psychology in 2021.

I have an interest in systemic models of working, and recently completed Foundation Level Training in Systemic Theory and Practice (accredited by the Association of Family Therapy).

The Adult Red Cell Team

NHS
King's College Hospital
NHS Foundation Trust

Red Cell Consultants

Dr Moji Awogbade | Dr Arne De Kreuk | Dr Sara Stuart-Smith

Red cell Clinical Nurse Specialists (CNS)

Lead CNS
Carole Rose

Clinical Nurse Specialist
Fester Ike

Clinical Nurse Specialist
Virginia Tshibangu

Community CNS
Yvonne Owusu-Sekyere

Other team members

Advanced Nurse Practitioner
Nina Gorman

Psychologist
Gary Bridges

Social worker
Rachel Davidson

Lead nurse for patient blood
Kelly Nwankiti

The adult red cell team at King's has expanded over the last year, and now consists of three consultants, three full time Clinical Nurse Specialists (CNSs), a community CNS, an Advanced Nurse Practitioner (ANP), a Social Worker, a lead nurse for patient blood usage and a psychologist.

Early next year, we will appoint a second psychologist to enable all patients to have access to psychology services when required.

Gary Bridges, our current psychologist, will be taking up a more senior post at Princess Royal University Hospital , but will continue to help out with our services one day a week until the appointment of two new psychologists.

Meet Your Haematology Team at GSTT

NHS
Guy's and St Thomas'
NHS Foundation Trust

Professor Jo Howard
Lead Consultant Haematologist

Dr Rachel Kesse-Adu
Consultant Haematologist

Dr Heather Rawle
Consultant Clinical Psychologist

Dr Abbie Wickham
Clinical Psychologist

Dr Kate Gardner
Consultant Haematologist

Dr Gulnaz Shah
Consultant Haematologist

Dr Georgia Parratt
Clinical Psychologist

Dr Emily Barrasin
Clinical Psychologist

Dr Samah Babiker
Consultant Haematologist

Dr Nita Prasannan
Consultant Haematologist

Dr Emma Sanchez-Walker
Clinical Psychologist

Dr Kiran Bains
Health Psychologist

Ms Olushola Shoyemi
Advanced Nurse Practitioner

Ms Haidee Nicasio-Laughton
Clinical Nurse Specialist

Shaira Chowdury
Community Specialist nurse

Mr Neill Westerdale
Advanced Nurse Practitioner

Ms Emelda Onah
Clinical Nurse Specialist

Mr Daniel Nyakutsey
Specialist welfare advisor

Will Tamblyn
Senior Assistant Psychologist

Isabella Rahman
Honorary Psychology Student

Ms Anne Oddote
Personal Assistant to medical doctors

Blood Transfusion in the haemoglobinopathies

Blood transfusion plays a significant role in the treatment of thalassaemia and sickle-related complications.

Transfusion of red blood cells increases the oxygen carrying capacity of the blood to allow delivery of oxygen to all tissues. In both sickle cell and thalassaemia disorders, people can experience anaemia, with a reduction in haemoglobin. Transfusion helps reduce this and can help prevent or reverse sickle related complications such as acute chest syndrome or vaso-occlusive crisis.

People with Sickle Cell Disease produce red cells that can 'sickle' making it difficult for the red cell to pass through small blood vessels to deliver oxygen to tissues. The red cells also have a shorter life span. People with thalassaemia do not produce enough haemoglobin, resulting in severe anaemia.

The Decision to Transfuse

Those with transfusion-dependent thalassaemia (e.g. beta thalassaemia major), require regular transfusions to prevent severe anaemia.

Those with sickle cell disease sometimes require transfusion as part of the treatment os a sickle-related complication, for example acute chest syndrome.

Some may need repeated transfusions as part of their ongoing care e.g. regular 'top up' or 'exchange' transfusion programmes following abnormal transcranial Doppler in childhood, or following a stroke, in order to prevent future complications.

The decision to transfuse in thalassaemia and sickle cell will be a discussion between the medical team and the patient.

Benefits and Risks of Blood Transfusion

Transfusion is relatively safe and the risk of serious harm associated with transfusion is very low,

Blood donors undergo rigorous screening, including testing for viruses like HIV and hepatitis. Blood is carefully selected and cross-matched for each person requiring transfusion in order to reduce the risk of complications. Reactions are usually mild temperature rises, chills or rashes, managed with paracetamol and antihistamines.

Patients with sickle cell are at increased risk of developing red cell antibodies after transfusion and more extensive matching is required to reduce this risk. The symptoms of red cell antibodies reacting against transfused blood includes fevers, pain, coca cola coloured urine due to haemoglobin in the urine, and localised loin or back pain. If you experience any of these side effects after transfusion you should let your doctor know immediately.

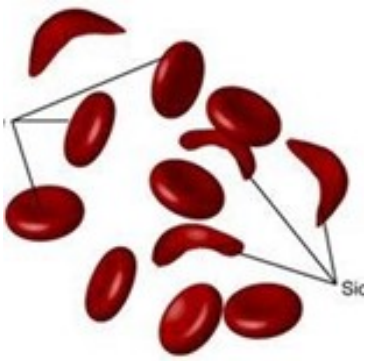
It is also important to let your team you know if you have been transfused elsewhere.

More Information

If you need further information regarding transfusion and how it may affect you, please speak with your doctor. If you are admitted to the ward you can also ask to speak to the Transfusion Practitioner at your hospital.

There are also patient information leaflets about transfusion in sickle cell disorders, including automated red cell exchange.

Kelly Nwankiti (Lead Nurse Blood Transfusion KCH)



To request further patient information please email : kch-tr.transfusionpractitioner@nhs.net

UKTS-Medical Conference Press Release

On Wednesday 27 October, the charity United Kingdom Thalassaemia Society (UKTS) hosted its first-ever virtual scientific meeting for medical professionals who were keen to learn more about thalassaemia. The event surpassed all expectations with over 120 participants attending from almost 60 hospitals. The four-hour meeting included a programme of talks by eminent experts in the field of thalassaemia, including Professor Baba Inusa, Dr Farrukh Shah, Dr Julian Waung, Dr Shivan Pancham, Dr Navdeep Kumar and Giselle Padmore - Payne

A range of topics pertinent to the condition were covered, including: bone and endocrine health; dental care; current steps being implemented to improve services; and ways to tackle issues during the transition process for young adults (from paediatric to adult services). There was also a presentation about the new therapies that are currently being developed and trialled.

Despite the recent disappointing news that the company bluebird bio – who successfully trialled a gene therapy treatment for thalassaemia – is closing its operations in Europe, there are a number of exciting developments in the pipeline in terms of new therapies for people with thalassaemia.

Many of these are showing really promising results, with the anticipation that they will enable people who have the condition to live transfusion-free, once treated. These are innovative times in the world of thalassaemia and there is every reason to be hopeful for life-transforming treatments on the horizon.

There were active Q&A discussions at the end of each talk and feedback was extremely positive. Attendees said they had learnt valuable new information from the talks that they would relay back to their own teams and incorporate into their working practices. Many also expressed an interest to get more involved with the work of the UKTS.

UKTS Chair, Gabriel Theophanous, said: "It is wonderful to see so many health care professionals keen to expand their knowledge and understanding of thalassaemia. Living with thalassaemia is hard, with dependency on regular blood transfusions and other interventions. By sharing knowledge and learning, haemoglobinopathy teams across the UK will be even better equipped to provide tailored care for people with thalassaemia leading to even higher standards of treatment. Thank you to the wonderful speakers who gave their time to share their expertise and to all those who attended. By working together, we can improve the quality of life for all those in the UK living with the condition."

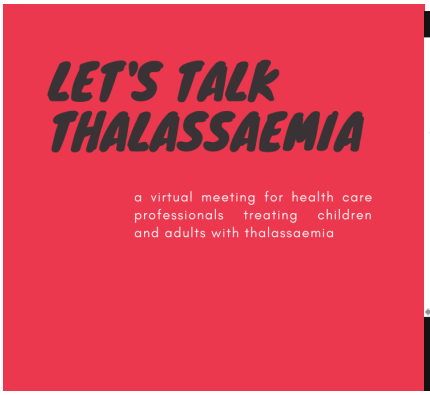
Thalassaemia is an inherited, chronic blood disorder affecting the genes that are responsible for production of red blood cells. Patients with thalassaemia are often dependent on regular blood transfusions throughout their lives. Without them, many would die in early childhood.

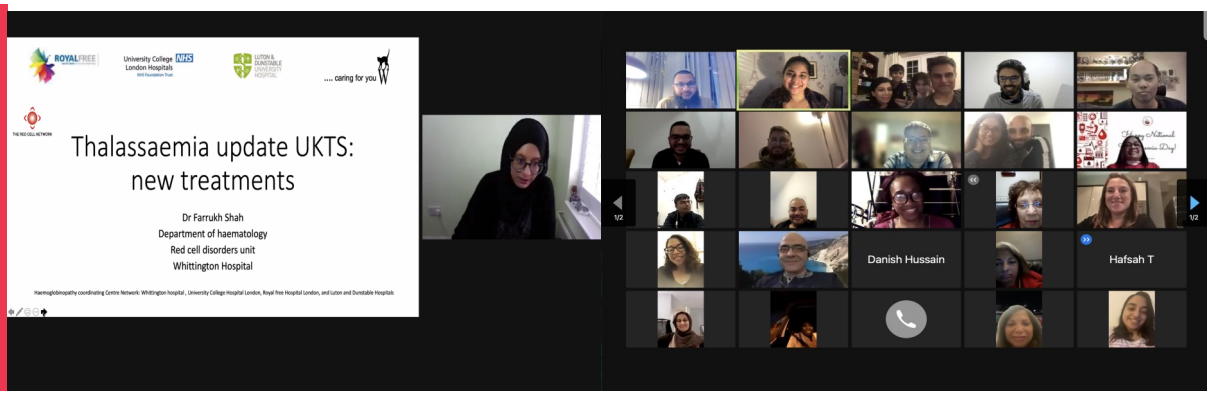
Thalassaemia developed as an evolutionary response to malaria which is why it mainly affects those coming from regions such as Asia and South-East Asia, the Mediterranean, South America, the Caribbean, Northern and Central Africa and the Middle East. Whilst it was initially prevalent only in these regions, due to the migration of communities over the centuries, anyone can be at risk.

300,000 babies are born with thalassaemia every year. This is why it is so important to be screened to find out you carrier status before you consider having a baby. If both parents are carriers of beta thalassaemia, there is a one in four chance that their child will be born with beta thalassaemia major.

You can find out more about thalassaemia by visiting the charity's website www.ukts.org.

For further information, please visit www.ukts.org or contact UKTS Executive Director, Romaine Maharaj on 0208 882 0011.

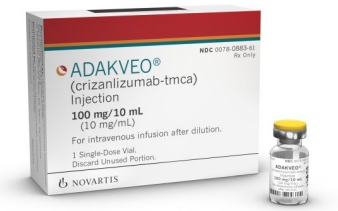




Crizanlizumab

On Monday October 4th 2021 the National Institute for Health and Care Excellence (NICE) gave the green light to a new drug for sickle cell disorder, crizanlizumab (brand name: Adakveo ®). After years of silence in terms of new drug developments, it is very exciting finally to have an alternative for sickle patients of 16 years and over who do not respond well to established treatment with hydroxycarbamide.

The drug is delivered by intravenous infusion 'drip' and works by binding to a protein in blood vessels and blood cells to improve blood flow and reduce the number of sickle cell pain episodes. It does not actually change the red blood cells themselves. Patients need to come back for the treatment on a 4-weekly basis and can continue treatment for as long as it is beneficial. Clinical trials and real-world experience show that on average, patients can expect a 40% reduction in painful crises and hospital admissions. Because the treatment is new and we need to continue building up experience, NICE approval requires that all patients are signed up for a so-called managed access scheme. This means that (limited) personal data will be recorded centrally to monitor safety and effectiveness of the new drug. We expect to be able to treat the first patients early next year.



Sickle Cell Awareness Month

September is officially designated as World Sickle Cell Awareness Month - a month dedicated to raising awareness of sickle cell and celebrating the achievements of those living with sickle cell.

The goal of the annual international awareness month is to increase public knowledge and understanding of sickle cell disease, and the challenges experienced by patients and their families and caregivers.

The **Darrent Valley Sickle Awareness** event was organised by Alero Omaghomi and Mrs Grace Bolaji (parent support leader) with the support of the Valley Hospital Charity.

Below are a few of the names of some of the attendees from the Trust.

Louise Ashley - Chief Executive

Kalene Sheppard - Deputy Divisional Director of Operations

Julie Frake-Harris - Deputy Chief Executive / Chief Operating Officer

Dr Suresh Kumar – Consultant

Dr Chinwe Ude – Consultant

Sue Daniels - e-Communications Manager

lynn brooks - Head of Nursing

Lynn McSorley - Clinical Governance Facilitator

Darent Valley Hospital

Patient Zone

Patient Poem

Sickle is waking up every day,

knowing that your body will betray you

Sickle is being ashamed,

of the defect in your blood

Sickle is getting nine hours sleep, and waking up

exhausted with no energy to move

Sickle is telling loved ones you feel fine,

while ignoring the pain radiating in your arms, hips, and legs

Sickle is getting dressed for work, while your body is begging you

to slow down, just to stop

Sickle is pleading with employers not to sack you, when you

fall ill for the fourth time in two months

Sickle is being curled-up in the corner in pain, praying

that you won't have to go to hospital again

Sickle is consoling friends and family when you fall ill, while

all you can think of is the pain bursting

through your body

Sickle is convincing healthcare staff that you deserve a hospital bed,

despite not "looking sick"

Sickle is listening to doctors accuse you of drug-seeking,

when all you want, is for the pain to stop

Sickle is watching your friends and family live their lives, from the

restraints of your hospital bed

Sickle is restarting your life every two months, after a bout of

excruciating illness, and still be expected to be on par with your peers

Sickle is getting up from your hospital bed, with a drip in tow,

to find your nurse who you've been calling for pain relief for two hours

Sickle is losing your independence because you can, no longer

manage by yourself

Sickle is fighting to keep your spirits high, when all you want to do,

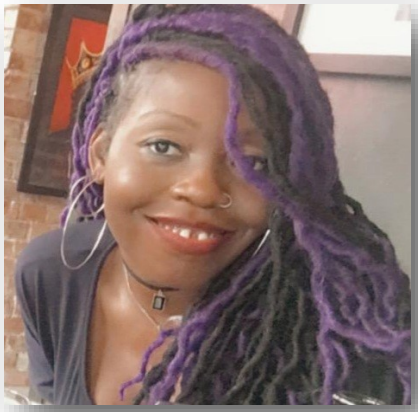
is crawl up and die

Sickle is fighting to stay alive, only to delay the

suffering, for just one more day

Sickle is knowing that one day, this disease will kill you, despite

fighting for your life, all of your life



Lily Nwamaraihe

@inside_ilianaike - Instagram and Facebook

Do you have a story to tell?

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

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.

YouTube