ISSUE (11) 2019 NEW YEAR EDITION

Happy New Year

South Thames Sickle Cell & Thalassaemia Network

KING'S HEALTH PARTNERS

Pioneering better health for all

RED CELL NEWS

2019 NEWS LETTER FOR SICKLE CELL AND THALASSAEMIA

IN THIS EDITION:

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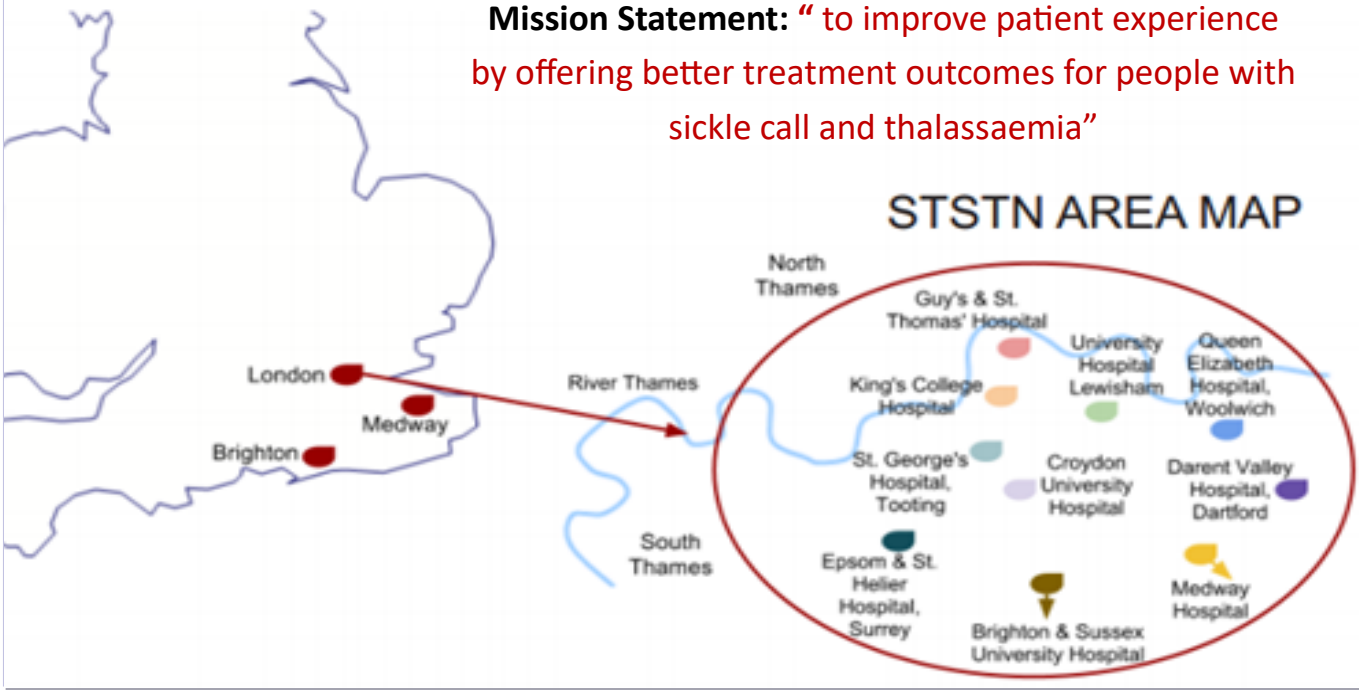
ABOUT STSTN

South Thames Sickle and Thalassaemia Network *is our local network which provides care for over 4,000 patients across 10 NHS trusts.*

Mission Statement: " to improve patient experience by offering better treatment outcomes for people with sickle call and thalassaemia"



STSTN NETWORK PRESENTS THE 11TH ISSUE OF RED CELL NEWS 2019!

We've started 2019 feeling very excited about the year ahead especially after recruiting Daud Daud as the new STSTN Network Manager and was appointed at the end of July 2018. Daud comes from a finance background with 12 years of experience however has worked within many sectors including the NHS. Daud is originally from Bristol and is also a member of the sickle cell and thalassaemia society in Bristol.

Plans for educating health care professionals across the region are well underway with the next STSTN Red Cell Course for haematology specialist trainees scheduled to take place in 2019, nursing and allied heath professionals courses and Patient Forum and Transition events. For more information please visit ***www.ststn.co.uk.***

Daud Daud
STSTN Network Manager

RED CELL NEWS NEEDS YOU

Do you have a personal story about your experience with sickle cell or thalassaemia that you would like to share?

Or an event you would like to publicise ?

We would like to hear from you! info@ststn.co.uk

PATIENT ZONE

Visit **Patient Zone** on our website (www.ststn.co.uk) to find patient information, clinic times, support group information and previous editions of red cell news.

If there's something else you'd like to see in the Patient Zone, let us know!

LONDON AMBULANCE SERVICE: "STATE YOUR EMERGENCY" "SICKLE CELL"

If you state your emergency as "**sickle cell**" when calling **999** you will automatically be given priority with an **8 minute response time** and a crew with a paramedic on board when possible.

LAS are updating treatment algorithms for sickle cell patients to reflect findings of a recent sickle user focus group which identified these three main priorities from sickle patients and their families: **rapid analgesia, offer of a chair carry to the ambulance, and transport to their chosen dedicated specialist treatment centre (rather than just the nearest A&E).**

You can ask your doctor to complete an LAS Patient Care Record outlining specific treatment plan, such as a morphine dose to be administered on the way to hospital.

2018 ASCAT CONFERENCE

The 2018 Academy for Sickle cell and Thalassaemia conference (ASCAT) ***'Bridging the Gap in Care and Research in order to improve outcomes for patients'*** took place in October 2018

STSTN EDUCATION MEETINGS:

Regular network education sessions for STSTN doctors, nurses and psychologists with sessions on "Vaccinations and Travelling with Sickle Cell Disease" in March 2018, Chronic Pain, Psychological management, and **Epidemiological research in sickle cell disease-related complications in Africa .**

UK HAEMOGLOBINOPATHY FORUM

The 2018 Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK were launched. The standards cover all aspects of the care of adults with sickle cell disease and are a joint venture with the Sickle Cell Society.

STSTN SICKLE CELL AWARENESS DAY

This July event was open to all Network patients and staff and featured teaching sessions on keeping well, updates on research, and patients sharing their experiences . Lunch and musical entertainment were provided

NETWORK NURSE TRAINING EVENTS:

RCN accredited "Introduction to thalassaemia and SCD" training days attended by 135 attendees from hospitals across the network

25 YEARS ON THE FRONT LINE

We thank Neil Westerdale, Sickle Clinical Nurse Specialist at Guy's and St Thomas, for his hard work and efforts providing the NHS with 25 years of service.

"My job is extremely rewarding and I feel lucky to be able to build these relationships with my patients and their relatives. I've treated some of them since they were babies and seeing them grow up and be able to manage their condition and have families of their own is fantastic".

Neil Westerdale
Specialist Nurse

PATIENT SUPPORT GROUP & PATIENT FORUM EVENTS

Many successful support groups are active across the network, and a program of Forum events aim to provide patient education.

The February Patient Forum event focussed on Stem Cell Transplantation and hydroxycarbamide therapy.

The November Patient Forum, was led by **Gary Bridges,** team psychologist at King's.

He talked about strengthening psychological well-being through positive psychology and focussed on enabling patients to thrive, not just survive.

Positive Psychology builds skills to enable people to flourish and create a life worth living.

Techniques include increasing positive emotions such as joy and pleasure; developing strong and supportive relationships; creating a sense of meaning and purpose in life; and doing things that result in a sense of achievement and accomplishment.

AND MORE NEWS

bjh guideline

Guidelines for the use of hydroxycarbamide in children and adults with sickle cell disease

A British Society for Haematology Guideline

Amrana Qureshi,[1] Banu Kaya,[2] Shivan Pancham,[3] Russell Keenan,[4] Jeremy Anderson,[5] Magbor Akanni,[6] Jo Howard[7] and on behalf of the British Society for Haematology

New guideline for use of hydroxycarbamide in children and adults with sickle cell disease published in May 2018 states "The benefits of hydroxycarbamide should be discussed with and treatment offered to all parents of children, adolescents and adults with HbSS/Sβ^0 to enable joint decision-making.

WHAT IS HYDROXYCARBAMIDE (AKA HYDROXYUREA) ?

Hydroxycarbamide is the only UK licensed medication for the prevention of recurrent painful crisis in sickle cell disease. In 1995 the randomised controlled multicentre trial of Hydroxyurea (MSH) showed that treatment could decrease episodes of pain and acute chest syndrome and reduce the need for transfusion. Other trials confirmed its effectiveness in sickle cell disease, including preventing disease complications and improving survival.

WHAT ARE THE SIDE EFFECTS?

Hydroxycarbamide is well tolerated with few side effects. Some experience mild gastrointestinal symptoms or increased skin pigmentation with darkening of nails. Some note mild hair thinning. Transient and reversible bone marrow suppression is a short-term effect and is also responsible for many of the clinical benefits.

HOW DOES IT WORK?

It slows down the bone marrow so more foetal haemoglobin, rather than sickle haemoglobin, is produced. This results in a reduction in sickle cells, improved haemoglobin levels, useful reductions of platelets and white blood cells, and reduced 'stickiness' of blood vessels.

WHY TAKE THIS DRUG?

It comes as an easy to swallow capsule taken daily. It usually results in significant improvements in haemoglobin levels, general wellbeing, a reduction in hospital admissions, episodes of pain, and the need for blood transfusions, as well as improving survival in patients with sickle cell disease. There is no associated increased risk of leukaemia or cancer in people taking this medications, even after 15 or more years of use.

WHAT OUR PATIENT HAD TO SAY ABOUT HYDROXYCARBAMIDE

"I had been admitted into hospital for a sickle cell related disease on more than 5 occasions the year before I began taking hydroxycarbamide, and now after 2 years on hydroxycarbamide, I have only been admitted into hospital once for 2 days. Before I was on hydroxycarbamide I would have been in hospital for up to a week.

Hydroxycarbamide has made a big impact on my health, significantly reducing the number of painful crises I have and the need for hospital treatment, resulting in a better quality of life for me as I am free to work and socialise as I please and not spend my time in the hospital.

As far as I know no side effects to this medicine have affected me. I would highly recommend others who are sceptical about trying this new medicine to try it as I was in the same position before making the decision to start taking hydroxycarbamide. ***I have to say it's one of the best decisions I've ever made."***

Opeyemi Oludairo

1978 to 2018

The society celebrated its 40th anniversary as a registered charity on 1st March 2018.

It was only when planning our celebrations that we realized that the history of the society was not formally recorded. We look back over some wonderful work undertaken by parents, patients and well-wishers over the last 40 years.

It all started in 1978, when parents were encouraged to register the society as a charity. Prior to that, affected parents were encouraged to start a group, meeting at each other houses, to support each other. They were encouraged by the doctors treating children with Thalassaemia Major, a severe and inherited blood disorder, which back then was accompanied by heart-breaking advice to parents to not have great expectations for a cure or normal life span for the affected child.

The diagnosis was very difficult for parents to process, knowing that it was because of their genes that their child had inherited the condition, and in order to survive their child needed regular transfusion and would still not be expected to survive past their 13th birthday.

Some parents could not even bring themselves to share the diagnosis with their closest relatives or friends, opting to try to deal with the problem by themselves. The first ever meeting was held at the home of Mary Christodoulou, a parent living in Camden Town. Mary's daughter Amanda was diagnosed a few years before. As soon as Mary understood that it was a potentially preventable genetic disorder, she started to educate everyone she met by speaking about the condition. She was surprised, while hosting the first meeting at her home, by the fact that she had neighbours who also had children with the disorder but had remained silent about their child's condition.

Nevertheless, parents started getting together on a weekly basis, using each other as support and strength to soldier through each transfusion and treatment.

They grew from strength to strength, changing the prognosis and lives for patients and their families.

We are extremely proud of our past and look forward to a future where thalassaemia major is just a chapter in a history book.

We will be uploading videos and other interviews on our website and social media platforms, so please subscribe to the various platforms/ our UKTS YOUTUBE channel. `

(From L to R) Sandy Brody, Francis Mate- Kole, Niamh Malone- Cooke and Emma Prescott with their awards

A cross section of the guests enjoying the presentation

Romaine Maharaj
Operations Manager
UK Thalassemia Society

Nora, a prize winning cake decorator, had exchange transfusions to allow her to travel safely to USA for an important cake commission. Thanks for donating your fabulous cakes to our King's Sickle Cell Support Group Christmas party!

Portia, whose pregnancy was supported by monthly red cell exchanges, celebrates the safe arrival of a beautiful healthy son, Paxton-Shane

WE SHARE YOUR SUCCSESS!

E-mail us your photographs and comments so they can be considered for the next Network Newsletter

Info@ststn.co.uk

COME ALONG TO YOUR LOCAL SUPPORT GROUP:

King's College London Hospital Adult Sickle Cell Support Group: Day: 2nd Thursday of the month, **Time:** 5:30pm – 7:00pm, **Venue:** Boardroom

Guy's & St. Thomas' Adult Sickle Cell Support Group: Day: Tuesday evenings, **Time:** 6:00pm – 7:30pm, **Venue:** GSTT Hospital Haematology Seminar Room. Also **Adolescent Group: Day:** Tuesday evening **Time:** 5.30pm-6.30pm **Venue:** Same

South East London Sickle Cell and Thalassaemia Centre: When: Last Friday of every month, **Time:** 10am-12:00pm, **Venue:** 5 Dugard Way, Lambeth, London SE11 4TH

Croydon Sickle Cell & Thalassaemia Centre: When: 3rd week in a month for coffee morning 11-1pm, 2nd Saturday of each month for service users and carers, **Time:** 11am-1pm for the coffee morning & 3.30pm-6pm for the service users and carers

No local support group listed? You are welcome to attend any Network support group

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