

RED CELL NEWS!

A newsletter for patients with Sickle Cell & Thalassaemia

Hello and welcome to the latest edition issue (issue 12) of the **STSTN Red Cell Newsletter!** I hope everyone enjoyed reading the New Year's edition which was published back in January (Issue 11). In that issue, we introduced Daud Daud, our new Network Manager who joined **STSTN** in July 2018. We looked back at some great events that took place in 2018 including the Network Nurse Training Event & the 2018 ASCAT Annual Conference. We also had an article on the UK Thalassaemia Society who celebrated their 40th anniversary.

There has been a lot happening within the **STSTN** network so far this year. We have had many successful educational events for medical professionals and also the annual Sickle Cell awareness day which you can read more about in this issue.

There have been a few staffing changes across the network this year. We would like to welcome back **Dr Stella Kotsiopolou** from CUH, who was on maternity leave and **Dr Kate Gardner** who has joined the network as an adult haematology consultant at GSTT. We would also like to thank **Dr Mina Abedian** from GSTT & **Natalie Cook** from KCH for all their hard work and wish them the best of luck for the future as they have now moved on to new posts outside the network.

I hope you all enjoy reading this issue!



Daud Daud
STSTN Network Manager



ISSUE (12)



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STSTN MISSION STATEMENT!

"To improve patient experience by offering better treatment outcomes for people with Sickle Cell & Thalassaemia"

MEETING THE CONSULTANTS



Dr Jo Howard,
Haematologist, GSTT



Dr Rachel Kesse-Adu,
Haematologist, GSTT



Dr Baba Inusa,
Paediatrician, GSTT



Dr Maria Pelidis
Paediatrician, GSTT



Dr Stella Kotsiopolou,
Haematologist, CUH



Dr Tullie Yeghen,
Haematologist, L&G



Professor David Rees,
Paediatrician, KCH



Dr Subarna Chakravorty,
Paediatrician, KCH



Dr Moji Awogbade
Haematologist, KCH



Dr Sara Stuart-Smith,
Haematologist, KCH

2019 STSTN EVENTS

STSTN EDUCATION MEETING:



We kicked off 2019 with an education event in March with a theme of “Respiratory Disease in Sickle Cell”. There was a good attendance of around 50 delegates and we

had some great presentations from guest speakers: Professor Anne Greenough from KCH, Dr Atul Gupta also from KCH & Dr Patrick Murphy from GSTT.



STSTN REDCELL HAEMATOLOGY TRAINING DAY:

We hit capacity for the first Red Cell Haematology Training day in March which is for specialist registrars and medical trainees. This is a haematology revision course with a specific emphasis on red cell

disorders, and looks back at recent exam papers to ensure that the topics most likely to be included in the exam are covered by the course. This is a very interactive course that includes case studies, past exam questions and a very encouraging atmosphere for participants to ask questions to our expert speakers.

Sickle Cell Awareness Day:

We would like to thank everyone who attended our annual sickle cell awareness day in the community on the 3rd of July. This was held at The Crypt/Inspire Church in Camberwell. We had a great turn out of around 80 people with some wonderful presentations from medical professionals and from our patients. We also had some great live entertainment from Nelenia Papisarva, a finalist from the Eurovision song contest in 2015, and a beautiful performance from Shekayla Blaze, a very talented gospel singer.



I've had sickle-cell all my life and it's not been easy. I've had to learn to roll with the punches that this ailment has given me. I've been in and out of hospital since I was tiny, and I've noticed all the changes over the years. I can't believe that I'm writing this, I sound very old where I'm looking back through time on how things used to be. I remember travelling in an ambulance, which is not like what we have now, and being in hospital and having the saline drip up. Back then it was kept in glass bottles. Today you have plastic squeezable disposable ones. Being on the wards, we had a Matron Sister, Staff Nurse and nurses in their proper uniforms with their aprons and little white nurses hats which had to be starched so that it would stand on their heads with hair clips in. The ward was a long ward, no cubicles, and the nurses would sit in the middle of the ward, male and female on either side. When you came into the hospital entrance and onto the wards you could smell the disinfectant right away, that's how

clean the hospital used to be. There was never such infections as MRSA about, but now there's all sorts and you're being discharged before you're completely better to prevent you from getting any other infections.

I remember breakfast. Wow...! Breakfast was real breakfast, not like today. It was a real English Fry Up. There was Bacon and Eggs with baked beans and fried bread; Fruit Juice, Tea or Coffee. Lunch was really nice too with things like Roast Beef and Yorkshire Pudding with Roast Potatoes, Carrots or Peas, and dessert would be Apple Pie and Custard etc. It was real healthy food.

Then came even more changes. The hospital was changing on the inside. They were making new wards. I just so happened to be in hospital at the time of the change over from the old wards to the new ones. I was transported in bed by a porter to one of these new wards.

They were now cubicles with four beds in each, with new lighting, TVs

which you had to pay for to watch, the beds were different now also, you could press a button and it would sit you up, or lay you back down again. There were separate washing facilities, everything was more secluded now, including the nurses section.

Things were changing fast, I remember calling for a nurse and was greatly surprised to see a male nurse come to me, but hey, it's equal agenda roles now. Nurses stopped wearing their uniforms and started to look more like civilians with only their name tags and fob watches on. And that is how it was and is now still to this day. In the present day looking back, things were so much better. Oh how I miss the good old days!



Marcia Brown

International Thalassaemia Day!

New APPG for Thalassaemia

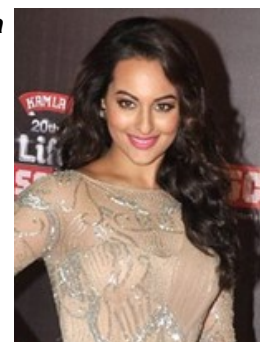
Wednesday 8th May 2019 marked International Thalassaemia Day and supporters from around the world were busy raising awareness of Thalassaemia to mark this special day for the global Thalassaemia community. It was a particularly special day for our UK charity and all of its members, because an All Party Parliamentary Group (APPG) was created for UKTS, to represent all those living with the condition.

Members from our charity were invited in to the Houses of Parliament to speak to MPs about this serious, genetic blood disorder. Bambos Charalambous, MP for Enfield Southgate, led the way for fellow MPs to raise awareness of Thalassaemia and was voted Chair of the APPG. Officers for the group will be duly elected. Working together with UKTS, the APPG will provide a valuable platform to discuss the different challenges faced by patients, their families and medical professionals in the field. **Some 30 MPs met with the UKTS team to learn about the condition and show their support.**

Mr Charalambous said, "I am delighted to be Chair of the APPG for such an important cause, one that resonates with many of my own constituents." Romaine Maharaj, Executive Director of UKTS added "It is great to have the support of Bambos and the other MPs. We want to reach out and support all those with this serious condition. With increased understanding of Thalassaemia among the general public and in particular amongst high-risk groups, this condition could and should be consigned to the history books."

Bollywood stars spread the word...

Meanwhile, across the globe famous Bollywood stars got in on the act! Parth Thakur, an Indian national with Thalassaemia and the founder of The Wishing Factory, galvanised a number of stars to show their support and spread awareness to their fans through posts on social media. Famous names included Hrithik Roshan, Abhishek Bachchan, Sonakshi Sinha and Ayushmaan Khurrana.



Sonakshi Sinha



The UKTS team with MP Bambos Charalambous (centre) and Councillor Stephanos Ioannou (second from right)

For More Info you can visit: www.ukts.org

The 'Tree of Life' Group at Guy's Hospital (GSTT)

Sickle cell disease can interfere in people's lives, interrupting opportunities and impacting on quality of life, sometimes taking over their identity and leaving them feeling disconnected from those around them. There can be a strong focus or story about the person as a 'patient' and the problems in their lives.

The “Tree of Life” group uses a tree metaphor to help us think about and share the stories of our lives and ourselves not as problems, but in ways which make us build positive views of ourselves, by connecting our strengths, abilities, hopes and identities, beyond a diagnosis of sickle cell disease. The groups aim to enhance self-esteem and empower people to feel it is possible to reduce the negative influence of sickle cell in and on their lives.

At Guy's Hospital, people have been coming together to participate in a 'Tree of Life' group over three or four weeks to share their stories and build on positive views of themselves.

In the initial weeks, each attendee drew a tree, and used its different parts as a metaphor for the different aspects of their lives and identities. These parts are outlined below A:

Roots: the person's background, culture/family history, favourite places, a treasured song or dance.

Ground: Their daily lives and activities.

Trunk: Their skills and abilities.

Branches: Their hopes, dreams and future wishes.

Leaves: The significant people in their lives who may be alive or may have passed on.

Fruits: The gifts they have been given by others.

Flowers: The gifts they have given to others.

Together we discussed the ways we manage and protect ourselves and others during the 'storms' or difficult times that affect us.

In the final weeks, the group was invited to “witness” each other’s life stories through listening out for what they have learned from each other and any qualities they have appreciated in each group member. This was extended into our haematology waiting area where the trees were placed anonymously in a ‘forest’ and other people were able to comment.

The staff, patients and passers-by were interested and moved by the identities and stories shared A:

“There is someone more like me than I realised walking these halls”

“Interesting history”

“So well described”

“Powerful pieces”

“Amazing people”

"I come to the clinic on my own, reading these I felt less alone. Thank you."

“This tree gives me some inner peace” “Don’t change”

“So much love”

Attendees said that they found “drawing relaxing” and that the group has helped them to be able think more about their lives, strengths and achievements. They shared that they are “more than just sickle cell”, feel more confident in themselves and more connected to the future. People also felt more

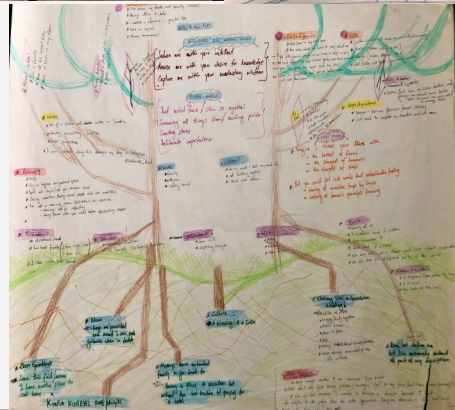
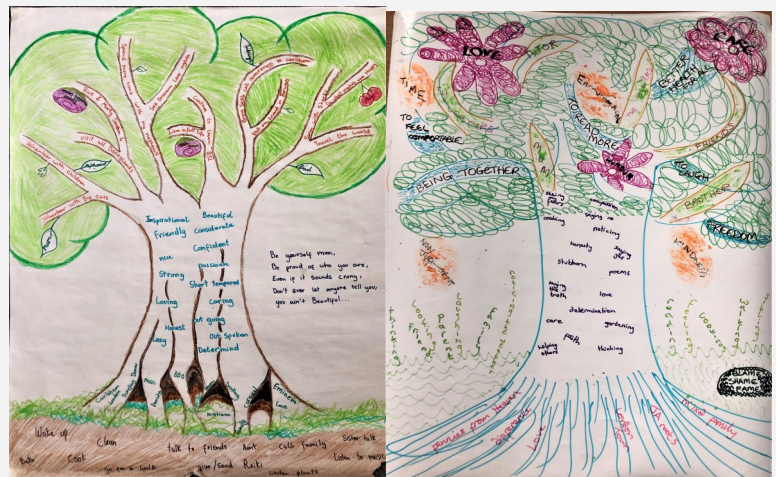
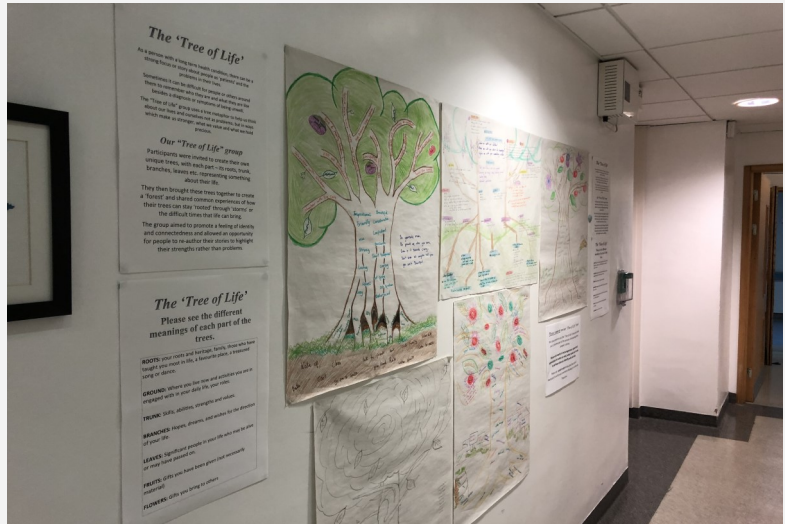
connected to others by sharing and learning from others with sickle cell disease. For example one person said “I am taking away the fact that all of us sickle cell patients, rather most of us, have similarities in the way we view our lives living with sickle cell.”

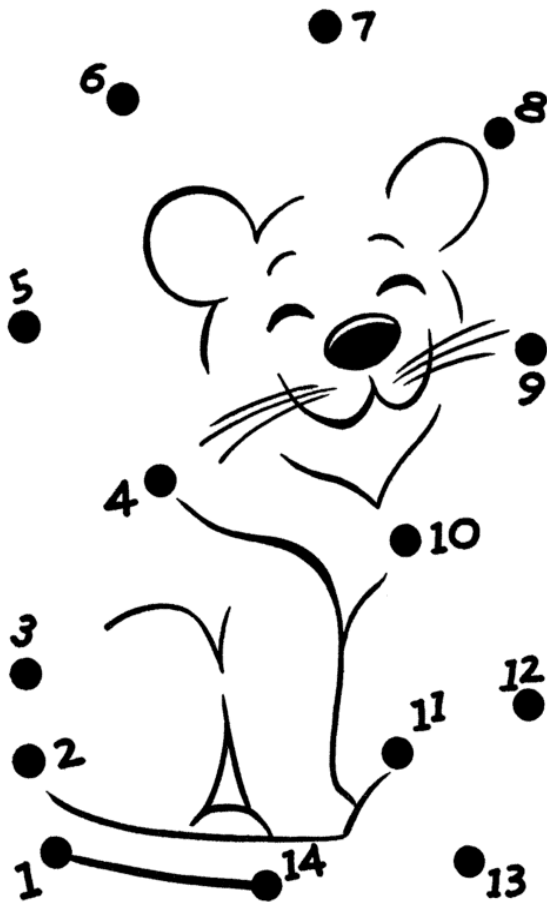
Our evaluations support the comments by our attendees in indicating that people were less stressed following each group, and the weeks overall, and showed an increase in their self-esteem from the first group to the last.

Why not have a go?

If you would like to have a go at doing your own trees at home, please follow the outline in figure 1, which shares which parts of the tree represent different aspects of your lives and identities.

If you are a patient or relative at Guy's and St Thomas' Hospital and would like to find out more about the groups we offer, please contact Dr Raselle Miller, Clinical Psychologist in the Haematology Health Psychology Service on 0207 188 2718.





Word Search

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

GIGGLE CORNER!



Q1) WHAT DO YOU CALL A PIG THAT KNOWS KARATE?

A1) ?

Q2) WHICH ANIMAL IS ALWAYS AT A GAME OF CRICKET?

A2) ?

Q3) HOW DO YOU MAKE AN OCTOPUS LAUGH?

A3) ?



BLOODCELLS
HEMOGLOBIN
HYDROXYCARBAMIDE
PENICILLIN
SICKLECELL
THALASSAEMIA

A1) Pork Chop!

A2) A Bat!

A3) With Ten-Tickles!

PATIENT INFO!

Pain Management Tips!

CONTROLLED DEEP
BREATHING EXERCISES

USE A HEAT PAD OR
TAKE A WARM BATH

TRY TO DO
SOMETHING THAT
TAKES YOUR MIND
OFF THE PAIN

DRINKING PLENTY,
STAYING HYDRATED

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?

Do you have an event you would like to publicise or would you like to connect with other patients through support groups and forums?

*Then we would like to hear from
you! info@ststn.co.uk*



PATIENT ZONE

Visit the 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!

COME ALONG TO YOUR LOCAL SUPPORT GROUPS:

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, Except the last Tuesday of the month when its 1-2pm

Venue: GSTT Hospital Haematology Seminar Room

South East London Sickle Cell and Thalassaemia Centre

When: Last Friday of every month

Time: 10am-12:00pm

Venue: Wooden Spoon House, 5 Dugard Way, Kennington, 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

Venue: 316-320 Whitehorse Road, Croydon, CR0 2LE

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

