Issue 9 October 2017

KING'S HEALTH PARTNERS

Pioneering better health for all

South Thames Sickle Cell & Thalassaemia Network

red cell *news*

A newsletter for patients with sickle cell disease and thalassaemia

About STSTN

The South Thames Sickle Cell and Thalassaemia Network (STSTN) is a haemoglobinopathy collaboration led by Health Professionals including consultants, nurses, psychologists, counsellors and others at King's College Hospital, Evelina Children's Hospital and Guy's and St Thomas' Hospital NHS Foundation Trusts and includes hospitals in London and the South East of England.

Our mission is

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

Visit www.ststn.co.uk

Hello and welcome to the latest issue of Red Cell News!

It's been a busy summer for the Network as we've organised and attended a huge number of events. From the King's College Hospital Patient Forum, to Guy's and St Thomas' annual Awareness Day, to our Exam Revision Day for Specialist Haematology Trainees and a training course for nurses and allied health professionals (more on that on page 5).

For this issue I caught up with Kehinde Salami, founder of SickleKan. You can read the full interview on page 3. We've also got a poem written by Bimpe Yakubu, a book review, service updates, research news and so much more!

Don't forget to visit our website for the very latest news, updates, and events. You can also find out more about what we're up to on a day to day basis on our Twitter page (@STSTNetwork).

We hope you enjoy this issue—there's lots here to get stuck into! If you would like to contribute or have any suggestions of what we should include in future editions, please do get in touch.

Eleanor Baggley
STSTN Support Manager

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!

In this edition:

Sickle Cell Society South London Link

A community service for individuals with sickle cell disease living in Lambeth, Lewisham and Southwark, or receiving treatment at hospitals within the South Thames Sickle Cell and Thalassaemia Network.

Free activities and social events

Support groups

Information and education workshops

Upcoming Event: 'Children in Education' Workshop for Parents, 4th November. Call 0203 879 9535 for more details.

Contact:

www.sicklecellsociety.org/sickle-cell-south-london-link-service

0203 879 9535

SICKLE CELL SOCIETY

My blood, My Life

The man shouted from the high pulpit,
"the life of a thing is in its blood"
And then the world faded away.
How, how could it possibly be true?
Where then has my life gone?

This life is no longer mine
To whom does this voice belong?
What these hands write, whose are they?
These words I speak, are they mine?
To whom do I owe this breath I take?

The blood in my veins is not mine
My black, misshaped blood is drained
Collected in a flat clear bag
A bag, fattened by the blood that failed
My life, oh my life, all in a bag

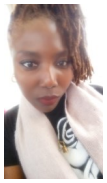
The whirring of the machine,
Its non-stop murmur numbs my thoughts
I count the bags of new life that pumps into me
At six, I become restless, my hand hurts
Receiving new life hurts. I close my eyes, three to go

I imagine a new name for each bag
Abdul, Sarah, Temi, Andrew, Chris, Yemi...
Oh, who knows but for the next six weeks
These are the people I would be
These are the people whose bloods are my life

The blood that gives me life is not mine!
My blood, sickled, old and tired, gave up
It no longer gave me life, it gave me pain,
Burning pain with no repentance
Hiding in my bones, silently crushing me

This new life too will be transformed
This blood will no more be called Sarah
Or Abdul, or Andrew, or Temi or Yemi or Chris
It would bear my name and it too would die
In six weeks, I would meet Paul, Tade, Amit

In six weeks, the cycle would start again
In six weeks, life would start anew
In six weeks, hope would be refreshed
In six weeks, I would close my eyes to the hurt
And let the whirring machine take over my mind.



By Bimpe Yakubu

Update from the London Ambulance Service

Earlier this summer the team at King's met with a representative from the London Ambulance Service to talk about emergency provision for patients with sickle cell disease.

State your emergency
If patients state that their emergency is "sickle cell" when calling 999 they will be automatically given priority with an 8 minute response time and a crew with a paramedic on board when possible.

The LAS are updating their treatment algorithms for sickle cell patients to reflect the findings of a recent sickle user focus group which identified the three highest priorities from sickle patients and their families from LAS. They were: rapid analgesia, offer of a chair carry to the ambulance, and transport to their chosen dedicated treatment centre (rather than just the nearest A&E). LAS are trying to make sure that these areas are covered in their updated guidelines.

Patient Specific Protocols
We are working towards providing emergency pre-hospital Patient Specific Protocols (PSP) for named patients, which will be held centrally and confidentially by LAS and communicated to paramedic teams when attending the home of a patient with sickle cell disease who has a PSP. This should enable specific requirements identified by a patient or their treating team to be adhered to during an emergency in a pre-hospital setting.

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.

Sickle Cell Awareness Day 2017

By Dr Katharine Bowen, Trainee Clinical Psychologist, GSTT Haematology Health Psychology Service

The 2017 King's Health Partners sickle cell awareness day was held on 19th July this year at St Thomas's Hospital. 54 people attended the event, which comprised of a series of talks from different members of the Guy's and St Thomas's NHS foundation Trust sickle cell team and service users, including medical issues, changes to welfare, and reflections on people's different experiences around living with sickle cell.

There was a wide range of attendees including service users, their families, and other members of health teams. Attendees had the opportunity to discuss or raise any questions, in order to get a better understanding of sickle cell disease and new developments in the area. The event was well received and having a wide variety of speakers was a valued part of the day.

If you have any suggestions for talks in 2018, please contact the Guy's and St Thomas' Haematology Health Psychology Service (heather.rawle @gstt.nhs.uk; raselle.miller@gstt.nhs.uk or mina.abedian@gstt.nhs.uk). We are looking forward to building on the success of this, and hope to see you in 2018!

An Interview with Kehinde Salami SickleKan founder

Tell us a bit about yourself and your experience of sickle cell
Hi, my name is Kehinde and my experiences with managing sickle cell have been up and down, as I didn't know that I had the condition until I was in my mid 20's. At that time I had a very serious sickle cell crisis episode while studying for my first degree in Manchester. I was rushed to the nearest medical centre to be told that I have the condition. I slowly remembered back to my childhood and the moments that I blacked out involved severe fevers, problems with fatigue, and temporary blindness. Now I understand that I was very lucky not to have had any serious or fatal episodes that could have killed me, considering that I wasn't taking medication or precautions to live with the condition. Besides that I have had mild to serious and life threatening sickle cell crisis episodes and just recently had to have an operation to restore sight in my left eye. This was due to a sickle cell episode that occurred in my eye, causing me to be blind for over a year and a half until it was corrected. I will say due to the unpredictable nature of the disease that it's a daily battle and I thank God that I'm able to live and tell my story while helping others.

Where did the idea for your charity, SickleKan, first come from?
Wow, I can remember the answer to that question quite clearly. This was after, let's say, the third of my serious back to back sickle cell episodes in November 2015. I had just had two life threatening episodes and had lost vision in my left eye and felt isolated, alone and on the verge of depression. Friends and family just couldn't understand the extent to which the condition was affecting me. I sometimes felt like a slave to my body constantly breaking down and sometimes considered overdosing on the medication to ease the pain. However, something clicked in my head and I started looking for information online and support groups and decided to be bold and create the SickleKan movement to increase the support network, to help sufferers like myself have a voice, and to share my experiences to encourage others to also speak about the condition, whilst breaking the common misconceptions about the illness. I started with Instagram by posting facts about sickle cell and my experiences, which led to people reaching out across different countries. Then I decided to post on various platforms and got support from so many people affected by the trait as well as the full blown condition and we just gradually collaborated to have the charity that we have today. Every day I am thankful for the support of the people that helped us from the start and are continuing to till this day.

What are SickleKan's aims?
Our primary aim was to provide a platform for patients like myself to have a voice, share experiences and tips on managing the condition, as well as help support patients like myself with the condition. We also wanted to support other institutions such as hospitals, schools, colleges, universities and businesses use adaptations and recommendations to help facilitate service users/students and employees in their care. We want to also provide research to help improve medicines and cures as well as support and talk about the often forgotten medical effects of dealing with such an intense illness.

What is your role with the charity?
I am Founder and Director of the charity alongside my Co-director Iman. But most importantly I am a patient affected by the condition who is also the father to a daughter that has the condition. With that and my youth and community work experience, I would like to see myself preferably as a mentor to adults and children that have the condition. However, Sicklekan is bigger than me and we also have Co-director Iman who has helped me run this charity with her valuable experience, as well as volunteers and other organisations that have helped us along the way.

Has founding SickleKan impacted on how you experience sickle cell personally?
Most definitely it has; as a small charity we have sometimes tried to do so many things at once that it has led to exhaustion, being overrun due to our passion to help as many people as possible. I have attended events while having a sickle cell crisis and have also had to take very strong pain killers to keep very painful episodes at bay while working on projects and meeting people. However I feel that knowing my body's limits and the support and care received from the staff at King's College Hospital Haematology Unit has enabled me to do more for this charity than I would have in the past. The work is challenging but I wouldn't want it any other way and the team constantly strive to do what we can to help others with the condition, especially children so that they can have a better way of life.

Your daughter also has sickle cell disease – do you have any advice for other parents of children with sickle cell?
What I would say is that it's a joint effort with the parents and the children and to ensure that you are aware of the triggers that cause a crisis episode. The key here is to work with your child while empowering them to have the self-confidence to not only talk about the condition so family and friends can support, but also understand that they know that with the correct steps in place they can live as normal a life as possible. The importance of instilling this confidence early is key and will ensure that their future is bright, while also improving the understanding and support for young patients - which can only be a good thing.

What are your plans for the future of SickleKan?
Plans for the moment include continuing to expand our team so that we can do projects locally, nationally and internationally. One thing that we must understand is that patients in other countries don't have the same level of support or access to medication that we do so we will try to bridge the gap to see if we can help improve that aspect by working with the relevant charities. We also plan to increase the projects that we are doing here including a school program, community projects and even maybe a TV channel, community centres and regular patient advice forums at hospitals, just to name a few. However our vision for the future is very optimistic, which is the reason why we are looking for businesses, organisations and volunteers to help us to reach our goals.

Finally, how would readers of this newsletter get in touch if they wanted to find out more about your charity?
We can be contacted by telephone via 02033252832
Email Sicklekan.info@yahoo.co.uk
We are also very active on social media via Twitter, Facebook and Instagram under 'Sicklekan', while our website address is http://www.sicklekan.com/
We also have a gofundme and paypal pages http://www.gofundme.com/sicklekan and www.paypal.me/sicklekan

SickleKan

Paediatric Sickle Cell and Thalassaemia Psychology Team: Who Are We and What Do We Do?

Dr Hatel Bhatt and Dr Natalie Cook joined the Paediatric Sickle Cell and Thalassemia Team earlier this year. We are excited to be part of the team and to be able to support children, adolescents and their families with Sickle Cell Disease (SCD) and Thalassemia. We are both qualified psychologists who are specialised in being able to support children, adolescents and their families who might experience a range of difficulties with their emotional well-being, as a result of having a lifelong chronic health condition.

Role of psychology in SCD and Thalassemia

Our role is to provide psychological support to children and young people who are living with SCD and thalassemia, and their families/ carers who are supporting them.

Children, young people, and their families can experience difficulties when trying to cope with the condition on a day-to-day basis. We are aware that living with SCD and Thalassemia can impact upon school, peer relationships, academic progress, and social and developmental aspects of growing up, and may therefore limit your quality of life. We are also aware that difficulties in these areas can, at times, impact upon your emotional well-being and contribute to feelings of sadness, anxiety and worrying. You may also experience feelings of being isolated from your peer group and/or family and friends, who may not understand how you are feeling. We therefore believe that psychological support can be beneficial to find effective ways to support children, adolescents, and their families with these challenges.

Therapy and assessments

Psychological support can be offered through individual and family psychology sessions at hospital or school; in some cases, we may facilitate home visits as well. Input from us can also be provided during your clinic consultation with the paediatric team and during your admissions.

Psychology sessions are used to develop ways to help with a range of things such as: pain management, coping with friendships, missing school due to hospital, and having a safe space for the child/young person to talk, as well as for the family to share difficulties they may have in coping. Specific support is provided to parents who may have difficulties with understanding the diagnosis and would like more information about support they can receive to help their children.

Psychological support can also be particularly important for children and young people, where psychologists are able to identify learning strengths and difficulties through neuropsychological testing.

Liaison with school and community services

In addition to psychological therapy and support, we will often liaise with schools to ensure that children and young people are provide with the appropriate support needed to engage positively with their education. This can be facilitated in many ways. We are able to provide neuropsychological/cognitive assessments that can help to inform educational heath care plans (EHCP), as well as assess the overall learning and emotional support that a child or young person has in school.

In addition to formal assessments, we can also take a role in organising school meetings to review school health care plans along with your community nurse. This can be particularly beneficial as we can assist schools in developing day-to-day strategies to support children and adolescents in school, as well as during more stressful periods in the academic year, such as exam times. We can also help to facilitate the process between hospital school and community school, with ensuring that school work is passed on during long periods of admission.

Other community teams

Our role as part of the Paediatric Sickle Cell and Thalassemia medical team also comes under a national and specialist service for *South London and Maudsley (SLAM) CAMHS- Child and Adolescent Mental Health Services.* This means that we can facilitate input from Paediatric Liaison CAMHS teams if needed, for more specific assessment or treatment for your child's mental health, such as, assessments for social communication difficulties, specific treatment for depression, anxiety, and other associated mental health diagnosis.

We also have good relationships with local community CAMHS teams, and can refer children, young people, and their families to these teams, if felt that this would be more helpful.

We also work closely with community nurse specialists to help provide holistic care, and help with the management of your health and emotional needs.

Transition to adult:

In addition to the above, psychological support might also be needed to help families and young people with transition from paediatric teams to adult teams. We form part of the transition clinic where we can to help facilitate the transfer of care process. We recognise that this time can be a difficult and anxiety provoking time for young people, and their carers/families.

As well as working closely with the transition nurse specialist, we also look to liaise with adult psychology teams that are associated with the Adult SCD and Thalassemia medical team. This is to ensure that there is a smooth transfer of care with respect to on-going psychological input, if required.

How can you be referred to us?

If you are interested in seeking psychological input for your child or family to help cope with their health condition, please speak to your medical team in your next consultation. They will then be able to refer you to us, or be able to offer you more information about our services.

Thank you

Dr Hatel Bhatt - Counselling Psychologist is based at St Thomas'/ Evelina Children's Hospital for the Paediatric Sickle Cell and Thalassaemia Team.

Dr Natalie Cook – Chartered Clinical Psychologist is based at King's College Hospital for the Paediatric Sickle Cell and Thalassaemia Team.

Visit our website (www.ststn.co.uk) to find out more about the psychology service, discover what support is available across the Network, and meet the team!

Going to University!

By Mary Crawford, King's College London

Many of you may be just about to start at university or college; this is a really exciting time but it can also be slightly scary. I want to give you a few tips about making your time at college really positive. One of the important things to remember is to tell someone if you need help.

You will know what your course is about before you start, but there may be some details which only become apparent when you get a bit further on! Try to find out if you will be moving to different buildings or going out on field trips, as you can then plan and avoid getting too tired.

Although each university is different, there will be staff who can provide extra support for students with a long term condition such as sickle cell disease. They may be called a learning support team or a disability team but the important thing is to get their support, regardless of what they are called!

There are specific things they can help you with to make your studying successful.

You will be allocated a personal tutor / study director (different universities use different terms) and it's important that you inform them that you have a long term health condition and how you think it may affect you. For example if you have several essays to be submitted at the same time, is it possible to stagger the submission dates? There will be a formal process by which to arrange this.

Most universities have a health centre and you can get good support from them. They will be used to supporting students and where necessary can liaise with your local consultant and team. If you need to miss some days at university because you are unwell or need to attend medical appointments, let your tutors know so you don't get marked as absent!

You may not want to tell lots of other students that you have a health condition but it is important for someone to know that if you don't turn up to lectures one day, you may be unwell. Try to find at least one person who will take notes for you if you are not feeling well and will also check up on you if you don't appear!

You may be living away from home for the first time so make sure you eat properly! If you haven't done much cooking before get someone to show you some easy, cheap nutritious dishes or look them up on the internet.

Enjoy your time at university as it will go so quickly: GOOD LUCK!

Educating Healthcare Professionals Across the Network

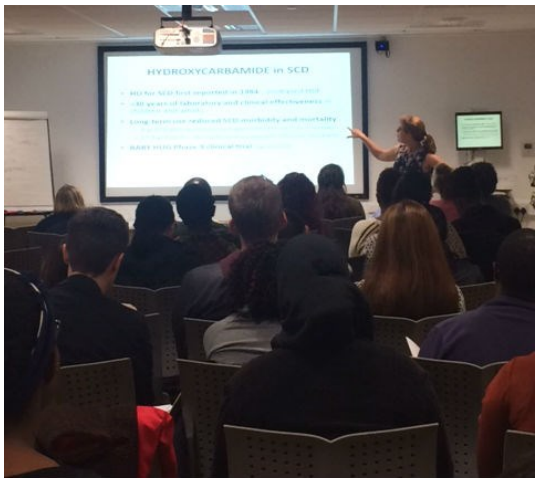
A concern commonly shared by people affected by sickle cell and thalassaemia is the lack of awareness and knowledge of the conditions among healthcare professionals across hospital departments. This issue has been raised by patients and carers at three events I have attended this summer – Guy's and St Thomas' annual Sickle Cell Awareness Day, a Patient Forum at King's College Hospital and a Transition Workshop at King's.

These groups of patients and carers of all ages felt that a health professional's awareness of sickle cell had an impact on the care they received. The South Thames Network and Greater London have the highest proportion of patients with sickle cell in the UK, which means it's imperative that staff across the hospital – from A&E to the wards – have an awareness of sickle cell and understand the implications of the disease.

In response to this, together with the team at King's and Guy's, we held a training course in September for nurses, junior doctors, and allied health professionals. Registration was open to any health professional from within the network region, whether or not they had any prior knowledge of the condition, and from any department.

The course ran for a single day and attendees had three dates to choose from. We were also successful in securing accreditation for the course from the Royal College of Nursing, which meant that attendees could gain points for Continuous Professional Development.

In total across the three days we had 133 attendees. The majority were staff from King's, but we also had staff from Princess Royal



University Hospital, Evelina Children's Hospital, Darent Valley Hospital, East Surrey Hospital, University Hospital Lewisham and Queen Elizabeth Hospital, among others.

We sought to reach members of staff from a range of departments and we certainly succeeded. Alongside staff of varying levels from adult and paediatric wards, we also had staff from A&E departments, physiotherapy, orthopaedics, ophthalmology, pharmacy, renal, and community teams.

It is our plan to deliver this course every year in order to continue to reach as many people as possible. We've already got a list of names for the 2018 course, even though the dates have not yet been confirmed. This is fantastic because it means that not only are we succeeding in our aim to raise awareness of sickle cell, but also that professionals from across the region are seeking that knowledge for themselves.

GBT 440-031 Study

By Dr Jo Howard, GSTT

The Sickle Cell Teams at Guys' and St Thomas' and King's College London are delighted to be participating in the GBT 440-031 study. This study opened in July 2017 in the UK and is an international multicentre study recruiting over 400 patients with sickle cell disease (SCD) from all around the world.

The GBT 440-031 trial is investigating whether a new medication (GBT 440-031) is safe and effective in reducing anaemia, pain crises, fatigue and other day-to-day symptoms in adolescents and adults with SCD. The medication is taken by mouth every day and is designed to keep the haemoglobin molecules in red blood cells from sticking to each other. This may help the red blood cells keep their normal shape and stop sickling. Early trials have shown that the medication is safe and that it may improve anaemia.

You can participate in this trial if you are between 12 and 65 years of age with SCD. You must have had at least one pain crisis in the past year. The study doctor and staff can explain other requirements for participation. If you enter the trial you will be randomly allocated treatment with the trial medication or a placebo (a 'sugar-pill'). You will be in the trial for between 2.5 months and 1.5 years, depending when you start.

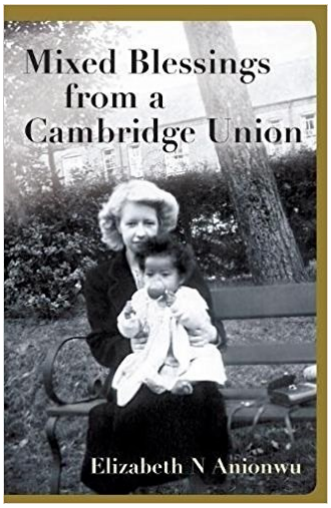
If you would like to find out more about the trial and if you are eligible to join please talk to your sickle doctor or nurses.

You can also find more information at http://www.globalbloodtx.com/pipeline/gbt440-sickle-cell-disease/

We have just launched a new research page on our website, which will feature all the latest clinical trials and research news: *www.ststn.co.uk/research/*

Book Review: Mixed Blessings from a Cambridge Union by Elizabeth Anionwu

Reviewed by Dr Moira Dick



Have you, like me, wondered how Dame Elizabeth Anionwu can have achieved so much as a nurse, educator, political and sickle cell activist? And remained so positive, non-embittered despite so many setbacks and with such a good sense of humour? Her book of memoirs (published in 2016 by ELIZAN Publishing ISBN 978-0-9955268-0-9) will give you some idea.

This memoir takes us from Elizabeth's conception all the way to the present day. Her mother, Mary Furlong, from a conservative Catholic working class family, was an exceptionally bright student who went to Cambridge University in 1946 to study classics. There she met a charismatic Nigerian student Lawrence Odiatu Victor and the inevitable happened. She became pregnant with Elizabeth. It doesn't take much imagination or knowledge of social mores in the 1940's to realise what happened next. Mary gave up her hard earned Cambridge University place, no marriage was forthcoming with Lawrence, and the Furlong family and the Catholic church found it hard to come to terms with the reality of a 'brown baby'.

However Elizabeth's mother and her family did evidently care a lot for her even if the grandparents pretended that they were fostering an unrelated child. Consequently Elizabeth spent time in a children's home, was looked after for a few years by her grandparents, and then went back to live with her mother where she was physically abused by her stepfather. Despite all this she maintained her sense of self and achieved her dream to become a nurse and ultimately a Professor of Nursing.

Being at University at the end of the 1960's meant that she was part of the heady days of student politics and in the early 1970's visited the USA, which expanded her views on life and politics. It was also at this time that she learnt about sickle cell anaemia, which was a major political and public health issue in the USA. She has been involved with promoting the cause of families affected with sickle cell anaemia ever since.

Pictured: Moira and Elizabeth

Perhaps unsurprisingly Elizabeth was also inspired by the life of Mary Seacole who, against all odds (she was also of mixed white/black parentage), supported service personnel on the Crimea, but her memory was subsequently eclipsed by Florence Nightingale. Elizabeth was instrumental in getting a statue erected at St Thomas' Hospital in 2016 in her memory and recognition of her legacy. Elizabeth was award a CBE (Commander of the British Empire), so is now a Dame as well as a Doctor. One of her friends suggested that CBE also stands for Cool, Black and Exceptional. I agree! Do read her book.