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

Hello and welcome to the latest edition of red cell news! It's been a while since our last newsletter and we are about due a catch up, so get comfy and I'll fill you in on everything that's been going on in the network.

I joined the team back in March as the new Network Support Manager. Since then we've been working on updating the website, building a presence on social media, planning events for the future, and coming up with new ideas for things that we can do to support patients throughout the South Thames region.

There have been lots of staffing changes across the network. Dr Moira Dick has retired after 35 years working with King's (more on that on page 6), Dr Sara Stuart-Smith has joined the adult team at King's from Lewisham, and we have a number of new psychologists working in the adult and paediatric services at King's, Guy's and the Evelina. I caught up with Gary Bridges, the new Counselling Psychologist in the adult service at King's, on page 3.

We have some fantastic articles for you in this issue, including a helpful look at the process for Personal Independence Payments from Welfare Support Advisor Daniel Nyakutsey, 'Crisis' a poem written by Yasin Saho, and Hellen Adom shares her experiences of growing up with sickle cell.

Make sure you check the back page for information about our upcoming awareness event at St Thomas' Hospital.

We welcome your contributions and feedback, so please do get in touch!

Eleanor Baggley
STSTN Support Manager

**In this edition:**




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@STSTNetwork


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!

**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"*

For more information visit www.ststn.co.uk

# Patient Corner

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.

**Crisis by Yasin Saho**

**Yasin's first poetry collection—Words Ascending by L.S Yasin—is now available on Amazon.**

***Crisis***

It creeps on you,
Starts with a tingling in the fingers, fooling you to believe it'll just linger.
The soothing mother
The nagging paramedics
The timeless nurses
The endless tears but not quite enough to describe the excruciating pain

The overcrowded A&E
The missing protocols
The overused doctors
And then the first needle goes in… nope that's not the one that 'kicks' in

It slowly spreads, from the numbing of the gum to the burning of the limbs.
Chest tight, joints slowly giving up
You wish for it to just consume you.
Sharp Scratch!
The continuous pokes, veins long faded
Same scene, different pain score
And then the needle goes in again
Eyes rolling back; yeeaaaah! The third dose does it for most

## My Life with Sickle Cell

## By Hellen Adom

I was born and raised in Liverpool, North West England. Growing up in cold conditions I soon learned how to brace myself and do my best to be a "normal person" by partaking in cross country runs (on rainy autumn days) in short gym skirts and ankle socks! However, there were days when doing such activities became too much for my frail body and I would end in crisis. I was aware something was wrong with me, yet did not fully understand to what extent this illness would bring into my future life.

As I grew, I started to attend hospital appointments on my own and ask my own questions.

One day as a wide eyed young woman around the age of 17, during a particular conversation with my consultant in Liverpool, they told me: "you do know most people with sickle cell rarely live past age 28."

I was shocked and distressed, though this was the main catalyst that started me thinking about what to do with the last 11 years of my life. A move to London was on the cards. However, my mother was not so keen, so it was another two years before I came to work as a nanny in 1984.

Sickle cell once again intervened and I found myself in North Middlesex hospital. On leaving that post, I met a dashing young man who was sympathetic and understanding of my sickle life. He became my future husband and although he knew of sickle cell in Ghana, which was his place of birth, he did not know he was AS. We found this out after the birth of our first child, who was AS. Three more children followed, two with SS.

Life was extremely difficult at times, especially if all three of us had crisis simultaneously. Divorce followed and the passing of my first child from meningitis. Three healthy children remain, two with sickle and an AS child. My interest developed in being involved in the field of sickle cell, becoming vice chair for Greenwich Sickle Cell Group, which founded the Expert Patient programme we see today. I have also sat on many health boards nationwide and am the named patient with the Sickle Cell NICE guidelines, which were created in 2013.

Having had a very poor education as a child, due to the amount of time off school, I was grateful for my Father's input. Always pushing me to do my best, he was a Math and English teacher, and would spend many hours encouraging and aiding me. As an adult I returned to education and have two degrees in the social psychology field. My Mother was a nurse, and taught me how to be relaxed and keep my mind active with sewing classes and shopping treats.

Being the eighth child of nine and one of three born with SS, I knew from early on in life I was somehow different from my siblings. Two of my SS siblings were born and raised in Ghana, making me the only SS child in the UK family. Both siblings have now passed away due to complications with sickle.

My children are now grown and have children of their own. This year a sickle baby came into our lives, and although we know he may endure pain, like me and my daughter who gave birth to him, we also know he may bring a world of knowledge in aiding the cure for sickle cell.

I have authored two books: "Nubian Minds" and "Curious Minds". In my book Nubian Minds, I have a section entitled "The Effects of Sickle Cell on Family Life" in which I interview three people with sickle cell and return to visit them six years later. You can find out what happens next by delving into my works on sickle cell awareness. More recently I have been unwell and have created a YouTube channel to keep active. Feel free to explore by searching for Elle Productions on YouTube.

**Gary Bridges**

**Counselling Psychologist**

**King's College Hospital**

My name is Gary Bridges and I have recently joined King's College Hospital as a psychologist within the Red Cell Haematology Service, where my role is to support people living with sickle cell disease and thalassaemia. Before this, I worked in a similar role at Homerton University Hospital in Hackney. I have been a psychologist for over 8 years, and I am also accredited as a Cognitive Behavioural Therapist (CBT) and an Interpersonal Psychotherapist (IPT), both psychological therapies that have a large amount of evidence for their effectiveness.

### Why is it important to have a psychologist working with patients with Sickle Cell Disease and Thalassaemia?

Psychological support is particularly important for people with sickle cell or thalassaemia because of the ways these conditions affect people throughout their lives. People often have to attend or stay in hospital regularly for treatment, which can have a big impact upon all areas of their lives, such as schooling and education, work, relationships with family and friends, and leisure activities. Studies have shown that, on average, people with sickle cell disease report lower quality of life in comparison to the general population, due to the impact of symptoms such as pain and fatigue. Psychology seeks to increase people's quality of life and find effective ways of managing their health condition.

Science is increasingly demonstrating the ways in which the mind and the body are linked and affect each other. People are usually already familiar with phrases which describe the mind-body connection in day-to-day life, such as something being a "pain in the neck", making your "blood boil", having a "gut feeling" or being "heart-broken". These examples all describe the way that the mind can affect the body. Research shows emotional states such as depression or anxiety have a big impact upon peoples' physical health, and so by applying psychological therapies such as CBT, or practicing mindfulness meditation, people can be supported to improve both their physical and psychological health.

### What can a psychology service offer people living with SCD/ thalassaemia?

The psychology service can support patients, families and carers in coping with the multiple challenges of living with sickle cell disease and thalassaemia. Meeting with a psychologist can help people by giving them the chance to talk through their difficulties and the impact they have on their lives, and explore how to best deal with these problems. Examples include, coping with pain in hospital and at home, adjusting to being in hospital or having to come into hospital frequently, overcoming symptoms of anxiety or depression, dealing with a fear of needles or blood transfusions, and coping with memory and concentration problems.

### How does psychology differ from other services?

Many people are often confused about the differences between psychology and psychiatry. Psychiatrists are trained doctors who have opted to specialise in the field of mental health. They tend to work mostly with people with more severe mental health problems. Due to their medical background, psychiatrists can prescribe medication.

In comparison, psychologists undertake a degree course in psychology and then go onto specialize in one of the many sub-fields of study. Psychologists work in a variety of different settings, such as in schools, in the workplace, in hospitals or in prisons, and work with a diverse range of people, such as those experiencing mild to severe mental health problems, people with health problems, people with brain injuries, with sports people seeking to improve their performance, and so on. It is becoming increasingly common for people to consult with a psychologist to enhance their well-being and performance. A psychologist will draw upon a variety of psychological interventions and do not prescribe medication.

**If you're interested in finding out what psychological services are available to you, speak to your medical team.**

## Adolescent workshop, 13th April 2017, Guy's Hospital

Luhanga Musumadi, Advanced Nurse Practitioner in Haemoglobinopathies at Guy's Hospital, has been organising workshops for teenagers and young adults with sickle cell for several years. This year's spring workshop, held at Guy's, featured short presentations on a variety of subjects relating to concerns that teenagers and young adults may have, including benefits advice and support at university.

The programme for this workshop was packed with interesting, informative and engaging talks. There were plenty of opportunities for questions and discussions with the speakers, but more importantly there were also plenty of opportunities for those present, a mixture of patients and parents, to talk and support one another. One attendee said that the "interaction in the group was fantastic," and another felt that "it was great to have questions answered and learn about the extra support I can get".

A community service for Individuals with SCD in Lambeth, Lewisham & Southwark

# SICKLE CELL South London Link

SICKLE CELL SOCIETY

## CHILDREN / TEENAGERS / ADULTS

Free Activities & Social Events

Support Groups

Information & Education Workshops

for those with Sickle Cell Disorders and their families

If you would like to find out more about our project activities register using the link below:

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

If you are interested in volunteering at a project activity email us at:

info@sicklecellsociety.org

LOTTERY FUNDED

Sickle Cell South London Link is funded by the BIG LOTTERY FUND and delivered by the Sickle Cell Society. Reg: 104 6631 Company Reg: 284 0865

**For information about other support groups in the area visit www.ststn.co.uk/patientzone/support.**

## DLA to PIP

**Daniel Nyakutsey MCMI**

**Welfare Support Advisor**

**020 3049 5993.**

If you are getting Disability Living Allowance (DLA) and it has been awarded to you for life or for an indefinite period, bear in mind that Department for Work and Pensions (DWP) intends to have all existing DLAs including life or indefinite awards reassessed. DWP will contact you and ask you to apply for Personal Independence Payment (PIP). What they will not tell you is that, although you have an indefinite DLA award, they will terminate it if, in their view, you are not sick enough.

You are probably wondering how they could do that when your condition hasn't changed. If anything, it may have worsened. The thing to remember is that PIP is points based, whereas DLA isn't. After you have completed the PIP form you will be given points at the medical examination you may be asked to attend. On some occasions the assessment would be done in your home. You need to score minimum 8 points to get the standard rates and minimum 12 points to get the enhanced rates of PIP. If you are awarded less than 8 points as a result of the medical assessment, guess what? You've just lost your indefinite DLA award. You will be left with no DLA and no PIP.

My advice to you is very simple. Start getting ready for the day DWP is going to ask you to switch to PIP:

- Keep all your hospital notes, reports, test results etc. handy.
- Get a diary and record how your condition is affecting your ability to do simple day to day activities (***Citizens Advice Bureau*** has a good template)
- Get help from someone who knows how to complete the PIP form. The PIP form may seem straightforward, but please don't take it for granted.
- Return the form to DWP with up-to-date information about your health and its impact on your day to day activities. Your hospital letters, reports and your diary need to go with the completed form to DWP.

PIP is all about the points. The first ***six daily activities*** on the form are the easiest to score points on for sickle cell patients. It gets harder from the seventh activity onwards because your ***cognition becomes a key factor*** for whether you are awarded points or not. If you are not able to explain how the chronic nature of pain inflicted by sickle cell disease might adversely impact your cognition and therefore your ability to carry out daily activities reliably, then you would risk losing valuable points on ***activities seven through to eleven***.

**Mobility**

If your current DLA award gives you the higher rate on mobility component, then the final two activities on the PIP form (eleven and twelve) are your only chance to retain this component. If you are not able to make the case that sickle cell pain adversely affects your cognition, then there is the possibility that you will not score any points on the eleventh activity. If you have a motability vehicle through your DLA then making the 12 points you need for the enhanced rate of PIP, ***the equivalent of DLA mobility component higher rate***, becomes very difficult because you may have to score all 12 points from the last activity.

Thousands of DLA claimants have already lost their motability vehicles because they didn't score enough points on the mobility questions. Getting help from a welfare support worker, although highly recommended, does not necessarily mean you would be awarded points for any of the activities. It does not guarantee that you would retain your entitlement either but at the very least, you would be better prepared and the PIP form would have been completed properly, avoiding some of the common mistakes most sickle cell patients make.

**PIP Descriptors**

PIP is a hard benefit to get because it was designed that way, but it can be done. Before you even begin to complete the form, ensure you know how the points are awarded (Google ***"PIP descriptors***" for a detailed explanation of what that means). Understanding the descriptors and how they translate into points will help you to organise information correctly on your PIP form. To put it simply: the words you use to describe how your condition adversely impacts your ability to do simple day to day activities reliably, both on the PIP form itself and at the medical assessment consultation, are what determine how many points you are likely to score.

Guy's and St Thomas' NHS Foundation Trust, King's College Hospital and University Hospital Lewisham provide a welfare advisory service through the South East London Sickle Cell and Thalassaemia Centre. If you are a patient of the above hospitals and you are worried about your benefits, get in touch with the centre. Clinicians, please encourage your patients to contact the centre for advice and assistance with the application process. Call Daniel on 020 3049 5993.

## Upcoming Events at King's

**Patient Forum**

Friday 14th July, 17.30-19.30, The Boardroom at KCH

**Transition Workshop (ages 14-18)**

Saturday 12th August, 11.30-17.30, The Boardroom at KCH

*To find out more about these events, please email info@ststn.co.uk*

## King's says farewell to Dr Moira Dick

This year Dr Dick has retired after 35 years of working with King's. Dr Dick first joined King's, then known as the Belgrave Children's Hospital, as a registrar in 1982. Since then she has worked tirelessly for children affected by sickle cell disease and thalassaemia, and has been at the helm of a number of important innovations to improve care. As well as a constant commitment to teaching and training, Dr Dick has promoted new models of care between hospitals and community services, fought for resources and funding for psychologists and specialists nurses, and developed guidelines and standards of care that are now used throughout the country. Dr Dick was also integral to the establishment of the UK Newborn Screening Programme to identify affected babies from birth, and ensure they and their parents receive early treatment, information and education.

Dr Dick's aim has always been to improve standards and ensure all patients receive the same care, no matter which hospital they attend for treatment. This aim led to the development of the first clinical network in the South Thames area, which has now become the STSTN!

Dr Dick's passion, support and determination cannot be overstated, and her contribution to King's and to the STSTN has been tremendous. We wish her a most relaxing retirement, but we're also very pleased that she'll be continuing to advise us in our work.

**Thank you, Dr Dick!**

*These photos were taken at an afternoon of talks and celebration held for Dr Dick in May—the turnout was truly a testament to all she has done for patients and medical professionals in this area.*

Would you like to share your experiences in red cell news? Do you have any comments or suggestions? Get in touch: **info@ststn.co.uk**

## Upcoming Event: Sickle Cell Patient Awareness Day at St Thomas' Hospital

On **Wednesday 19th July** come along to the **Governor's Hall at St Thomas' Hospital** for a day of talks and presentations to raise awareness of sickle cell disease.

The event will run from **11am to 4pm** and **lunch will be provided**.

Meet the team, hear more about new treatments, find out about the community services, listen to patient accounts and so much more.