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South Thames
Sickle Cell &
Thalassaemia
Network

red cell news

A newsletter for patients with sickle cell disease and thalassaemia

ISSUE 3 SPRING / SUMMER 2013

WELCOME TO THE 3RD EDITION OF RED CELL NEWS

WELCOME

At the time of writing it still feels we are in the depths of winter as the arctic weather front continues to test everyone's patience! We hope you are all taking care in this cold weather and fingers crossed the publication of our Spring/Summer issue of *red cell news* will be the catalyst for the arrival of some much needed warmth and sunshine.

In this issue you will find a short story from writer *Uzor Chinukwue* (right) and an interview with *Ade Adebisi* (below), rugby star with the London Skolars.



We also have an inspiring story from the *Croydon Sickle Cell &*

Thalassaemia Patient Support Group, a

rock in the sickle community.

Mrs Nkechi Anyanwu, Service Manager and Clinical Lead at the South East London Sickle Cell and Thalassaemia Centre, introduces herself and what the service offers. We hope you find this useful and we aim to bring you more information about other services that can support you from around the Network.

We also have an update on research studies from Professor Swee Lay Thein, plus some event news from the Health Psychology team based at the Evelina Children's Hospital.

If you would like to share a story, news article or feature or have artistic talent you would like to show off, be it drawing, photography or graphic design please get in touch with me.

Until the Autumn!



Annabelle Kelly
STSTN Support
Manager

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CROYDON SICKLE CELL & THALASSAEMIA PATIENT SUPPORT GROUP

By ALICE ALLISON (CHAIR)

At Croydon Sickle Cell & Thalassaemia Patient Support Group we are proud and passionate about serving our community. We have regular monthly group meetings on the second Saturday of each month except January and August. We also have social meetings where members can just come and share a meal and chat. Occasionally we invite speakers to speak on specific topics that will benefit the group. We also have a Young People group run for, and by, young people.

We are very fortunate to have a young girl who has sickle cell, but she is very positive, as you will see from the write up from her mum.

Read the full story of Sapphire on page 5.

ABOUT STSTN

The South Thames Sickle Cell and Thalassaemia Network (STSTN) is a haemoglobinopathy collaboration led by Consultant Haematologists and Paediatricians at King's College Hospital, Evelina Children's Hospital and Guy's and St. Thomas' Hospital NHS Foundation Trusts.

STSTN aims to:

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

Find out more at: www.ststn.co.uk

PATIENT PLATFORM

YOUR STORIES. YOUR NEWS. YOUR VOICE.



A SCARLET VIRUS, A SCARLET WORLD

by Uzor Chinukwue



'I can't see it,' Sarah said. 'Over there on the left. Do you see it now?'

Sarah gave a yelp of excitement; she'd just seen an unexpected but welcome sight through my binoculars – a settlement! In the distance a group of weatherworn shacks braced defiantly against desert winds. However, we were absolutely sure there'd be no one left in town for, you see, the world died three years ago.

Nevertheless, we continued onwards knowing a settlement meant a source for much needed supplies: water, food, medicine, and fresh shoes to walk in. And even as we laboured on the scarlet mist swirled around us, that thing that was now in our air, and that had killed everyone so long ago now. It always seemed like a dream somehow, a regularly recurring nightmare which we were forced to live everyday.

To survive, we had to wear protective chemical suits and haul a weighty breathing apparatus on our backs. We seem as the dead with little or no food, and all this heavy weight. We're skeletons in the mist, and I feel sick and desperately thin and I know that Sarah does too.

'We should refill our canteens in the town; mine's empty.' I now said.

'Mine too, but are you sure it's safe?' Sarah

replied.

I shrugged my shoulders in reply and took the binoculars from Sarah. I looked through them at what seemed an abandoned town, straining to see any signs of life or of danger.

'It looks deserted; we may as well risk it.'

Sarah didn't reply, but I imagined she'd be frowning under her mask.

'It's a risk we're going to have to take, Sarah; otherwise, we'll die of starvation.' I said defensively.

'If you think that's what we have to do, then that's what we'll do.'

'OK then,' I replied. At this point I was too irritated to care what she thought. I started down the hill and made for the village. Sarah followed closely behind.

The floor was parched ground; there was no life here. And even as we walked, the scarlet mist surrounded us. Like a medieval warlord besieging an ancient city to plunder it of its wealth, the mist hung over us, waiting for us to run out of oxygen. 'Oxygen!' I said out loud, kicking in frustration the blanket of scarlet dust that lay around us.

'What did you say?' asked Sarah.

'I said we need oxygen.' I replied, irritated that such an obviously important and vital thing had skipped my mind: but it's hard to remember anything on an empty stomach.

'We need to get to Zion city to refill our oxygen canisters; this detour will only delay us.'

Zion city was the last bastion of human hope, made by and for those who'd survived the wars and the virus. It was the one place where we could feel secure, its towers high where no terror could reach us to cause us harm. And it was the only place with the expertise to refill our waning oxygen supply.

'What do we do now?' Sarah asked.

'Well, we're already here. Zion can wait,' I

said. 'It'll be days before we get there.'

We slowed down to a crawl as we came up on the first row of houses, submitting to the sort of caution that can only come from experience. We stumbled upon a bar and entered. The taps were bone dry, but we found some precious water in a drum and applied ourselves to filling our canteens. Suddenly a blood-curdling scream reached us from outside. A thousand vague fancies gripped my soul and I was immediately struck numb.

'What was that?' Sarah said, her voice unsteady.

'We better not wait to find out.' I said scampering out of the bar. I fled, not knowing where my legs carried me, but nevertheless content they wouldn't fail me in this my time of distress.

I'd been running awhile when I suddenly realised Sarah wasn't with me. I stopped and called her name into the night. But there was no reply. Overcome with worry, I hurried back to the bar. Then I saw a pack of wolves feasting on her body. I rushed toward them, despising my fear and screaming at them. But the wolves, apparently immune to the virus, left their meal and gave chase.

Once again, I found an atavistic need to flee encapsulated somewhere within my soul, and I ran, until a pit found its way under my feet and I fell. Down I went till my hand found some purchase. I hung desperately on. The wolves, now at the foot of the hole, stared at me, their eyes shimmering red in the night. I felt myself going to sleep and heard the wolves speaking to me. They told me they were the demons that now ruled the earth. The scarlet cloud was sin, man's wanton violence, and the fear of death.

'Why go on' they said to me, tempting me with their words, and vexing my soul until at last, wearied, I conceded and removed my

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mask with my one free hand

They laughed wickedly, and the sensation of death overcame me. I was becoming a wolf, like the very enemy I despised and I emerged from the pit and joined the wolf pack.

Sarah then emerged suddenly from where she'd been hiding and I realised I'd been tricked with a sensory legerdemain. They'd tricked me into joining them, and now we had a new victim.

I enjoyed the meal with my wolf brothers and when it was over, I joined them in howling into the scarlet night.

*Uzor Chinukwue grew up in Lagos, Nigeria and has lived in London for 15 years. He self-published his first book, *The Mind that Father Made* in 2010. He has since written 2 more books that are awaiting publication, *The African Mist*, and *Hell Street*. Uzor is a patient at Guy's & St. Thomas' NHS Foundation Trust.*

Email: chinukwue@aol.co.uk

GET IN TOUCH

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

Are you a budding storyteller and would like to see your work in print?

Is there an issue about sickle cell disease and thalassaemia that you would like to discuss?

Do you have an event you would like to publicise or would you like to connect with other patients and create a support group?

Or would you simply like to tell us what you think of **red cell news** or suggestions of what you would like to see included.

Then we would really like to hear from you.

Get in touch with Annabelle by email or phone: info@ststn.co.uk or 020 7848 5441

Question time with London Skolar rugby ace, Ade Adebisi

26 YEAR-OLD, NIGERIAN BORN, ADE ADEBISI HAS DEFIED ALL THE ODDS AND PROBABLY THE WISHES OF HIS DOCTORS GROWING UP TO BECOME A SUCCESSFUL AND WELL RESPECTED, SEMI-PROFESSIONAL RUGBY LEAGUE PLAYER. OFF THE FIELD ADE HAS TAKEN



ON THE ROLE OF AMBASSADOR FOR THE SICKLE CELL SOCIETY AS WELL A SUCCESSFUL CAREER AS A SPECIALIST SERVICES SUPPORT MANAGER AT WILSON JAMES. ADE HAS FOUND TIME IN HIS BUSY SCHEDULE TO TELL US MORE ABOUT HIS DRIVING, AND DIVING, AMBITION.

Rugby league is one of the toughest sports there is - what drew you to playing it?

Ade: Well, my teacher at secondary school, Andy Hirst, saw the talent in me and he thought I could be a good player. Our school never had a rugby team, and he set one up because he believed in me. The physicality of the sport never bothered me, I loved it. But Andy really encouraged me.

When did your passion for rugby take off? Andy took me to my first rugby game when I was 14 and I never looked back.

Tell us a bit about your rugby career I play on the wing and I can also play full-back if needed. I currently play for London Skolars RL and in the past I have played for London Broncos, Hull FC, Doncaster, Featherstone Rovers and Whitehaven. In season, we train 3 to 4 times a week, including a match on a Sunday.

I presume your clinicians and family were not too keen on you taking up sport, especially rugby? What do you think propelled your ambition? No. Everybody tried to stop me when I was younger because of my sickle cell disease. I had two opposing views, the doctors and my family on one side and Andy, my teacher,

believing I could be a really good rugby player, on the other. When I played my first game, I felt great. I was tired, but I just trained harder. I knew I had the heart to do it. This driving ambition, from my heart, propelled me and I couldn't think of doing anything else.

What has rugby brought to your life? Rugby has brought everything I have in my life. Everything I do and have now is down to rugby; its part of me. My mental toughness, my drive to be a winner and my ambition to never to give up on what I want is all down to playing rugby.



Who has been your biggest influence in life on and off the field?

Steve Morgan, currently Commercial Director at the Ministry of Defence, was a father-figure for me. We met a long time ago, when I was playing for Whitehaven and he was Commercial Director of Sellafield at that time. We got on from day one, we connected, and he was like a father to me from the first moment. He's always pushed me and supported me on the field and he'd come to the games. But off the field he encouraged me to carve out a career and he helped me get my first job.

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What has been the lowest point of your career and what got you through these times?

I've had a few lows in my career when I doubted myself because of my sickle cell disease. When I was younger and I played internationally for the Great Britain Young Lions, the training was so intense. We'd do 10-mile runs and hill training. I thought some of the team presumed I was being lazy when I couldn't keep up, but I just couldn't carry as much oxygen, so I started to doubt whether I could keep up. But I pushed myself through it. My ambition, from my heart, kept me going.

What was it like for you growing up having sickle cell disease?

Growing up with sickle cell was tough for me as I was a sporty person. I found it hard to get about with fitness and didn't understand why I wasn't getting as fit as the rest of the kids.

You must have had some dark moments in your battle with sickle cell disease? How did you manage and keep positive?

Every game I go into, before the game, I always think I may let people down on the pitch. It's always a battle with myself that I have to overcome.

How does your medication impact on your career?

It's difficult. Because of the morphine I take, I have a special dispensation form that I have to complete, as we get tested before every game. Without that form, I would be banned for 2 years if they found morphine in my system. I have to keep details when and how much medication I take, which is hard. When I am in a lot of pain, it's difficult to care about filling out forms.

It also affects my physical fitness as the morphine makes me lethargic and out of breath. If I have been in hospital, I now make a gradual return to training and playing. In the past, I have been in hospital for 6 days and then I would play a game 2 days later. My coach gives me a

week off now. It's all about having a good management plan in place as I have learnt from experience what works for me.

How is your sickle cell disease at the moment?

At the moment, when I'm not training it's terrible. I'm in and out of hospital. But when I'm training I hardly go to hospital. My doctor has said this maybe because when you keep fit, you do generally feel better. I can't speak for others but the general view is if you do something hard, you generally feel worse. But with a good balance of training and a healthy,

supported me and I want to repay them for all they have done for me. It's really important to have that support, especially living with sickle cell disease.

What makes you happy?

Playing rugby, especially when we win, feeling fit and healthy, and care and support I have from friends, family and the team.

Tell us about your work with the Sickle Cell Society?

I was delighted to accept the position of Ambassador for the Sickle Cell

Society. My role is to raise awareness of the disease, make appearances at functions, help young people understand how to live with the condition and raise funds for research. I'm throwing myself into this new challenge because I know I've been fortunate in life with my rugby and the support I have had, so anything I can do to advise young people growing up with sickle cell disease I will do as my role with the Society

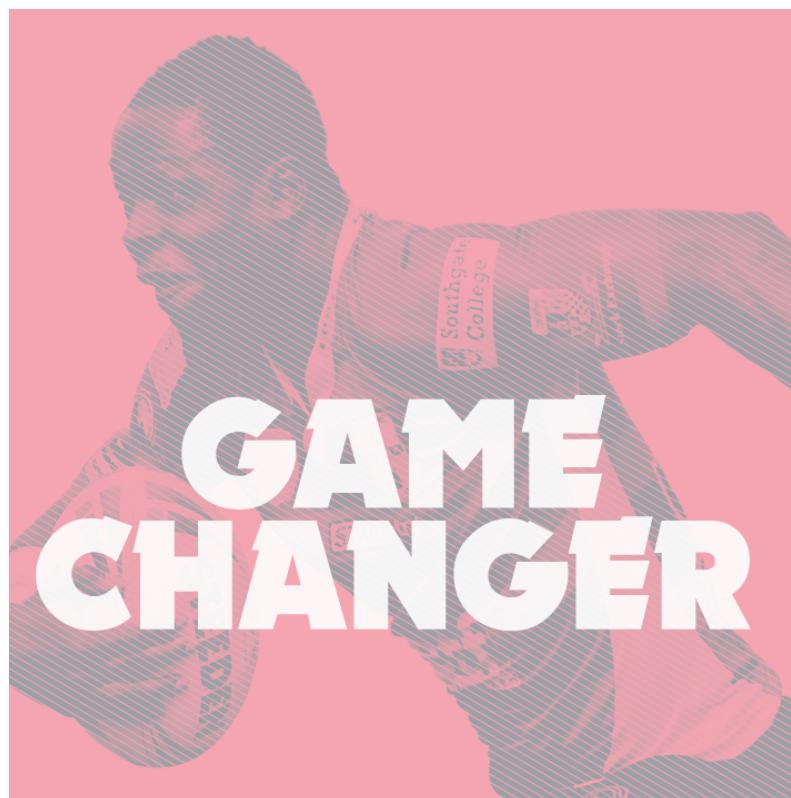
What are your future hopes and dreams?

Carrying on my role as Ambassador for the Sickle Cell Society. We are hoping to plan a prestigious gala event in October, which will be hosted by Steve Morgan and Dawn Butler, previously MP for Brent South. We are also hoping some high-profile celebrities will be in attendance. Watch this space!

Apart from that, to keep doing what I am doing, keep playing rugby and to further my career within Wilson James.

What message would you like to send to other sickle cell disease sufferers?

Don't let sickle cell stop you doing what you want to do. You can achieve your dreams and goals and never give up on them. Think about what you may have to do differently to those without sickle cell and learn how to manage it on an individual basis. Always ask for support and don't feel you can't ever ask for help.



nutritious diet, I find it makes me feel better.

Tell me a bit about your career off the field?

I work for Wilson James, a specialist aviation, construction and security company, as a Specialist Services Support Manager. They've helped me a lot in my career and they also sponsor my current team, the London Skolars.

The Chief Executive Officer, Mark Dobson, has supported me throughout my career at Wilson. I think I'm very fortunate in that I've had so much support in my life and have been given great opportunities. This is what drives me to keep going. I don't want to let down the people who have

PROFILE: NKECHI ANYANWU South East London Sickle Cell and Thalassamia Centre



I'm a highly motivated, dedicated, and an experienced nurse with sound knowledge of haemoglobinopathies. I joined Guy's & St Thomas in August

2012, as Service Manager and Clinical Lead (haemoglobinopathies) to provide strong professional and clinical leadership to a team of highly skilled, compassionate and dedicated specialist nurses.

I have worked with clients, their families and carers with sickle cell and thalassaemia, for many years and have a wide range of experience in the field. My previous roles, as a trained general nurse and midwife, has given me the foundation to build on my wealth of knowledge, working within this client group.

My role is centered on providing comprehensive services in different care settings to the residents of Lambeth, Southwark and Lewisham in delivering of high quality services, which is embedded in the team through national agreed standards and best practice within the haemoglobinopathy field.

I am excited about working in such a huge organisation with a strong network, who are pioneers in the field of haemoglobinopathies. One of my ongoing objectives is to continue to raise the awareness of these conditions amongst the local community in which we serve.

My role has many challenges which I look forward to embracing, working alongside the multi-disciplinary team in the detection and prevention of haemoglobinopathies.

ABOUT THE SERVICE

We aim to provide a high quality specialist nursing service to the residents of Lambeth, Southwark and Lewisham, who are "at risk" of having, or already have, an unusual haemoglobin type. We also provide the same service to individuals, families and carers who are affected by sickle cell and thalassaemia.

The services offered include:

- Genetic counselling to support the national and local Antenatal and Neonatal Screening Programmes
- Giving timely blood screening results to patients
- Case / Disease management for individuals with the conditions
- Health promotion and training for other

health professionals

- Supporting individuals to self manage their condition
- Pre-conceptual screening and counselling for general public
- Providing Education and Training Programme for the general public
- Resource and information centre (leaflets, articles, DVDs etc)

How to access the service

- Self-referral
- Via clinic or other professional service
- Via the National / Local Screening Programmes

WHERE WE ARE AND How To CONTACT Us

South East London Sickle Cell and Thalassaemia Centre,
Wooden Spoon House, 5 Dugard Way (Off)
Renfrew Road, Kennington London SE11
4TH

Office number: 020 3049 5993

Fax number: 020 3049 6069 / 6085

Email: gst-tr.referrals@nhs.net

Opening hours

The Service/Centre is open from 9am and closes at 5pm (Monday to Friday).

CROYDON SICKLE CELL & THALASSAEMIA SUPPORT GROUP

THE STORY OF SAPPHIRE (CONTINUED FROM PAGE 1)



Despite living with sickle cell disease and missing a lot of school due to illness and hospital appointments, 13 year old Sapphire thrives to be all she can be by being an outstanding student and member of society.

In her 13 years so far, Sapphire has had two poems published and won a number of awards including the Sickle Cell Society's Floella Benjamin Achievement Award at the 30th Anniversary AGM. She has gone on to

win Croydon Guardians Champion Child of Courage 2012 and Spirit of London Award Foundation Young London Hero 2012. On 16 January 2013 she had her wish granted by Starlight Children's Foundation and travelled with the family to Manchester to be team mascot for her football team Manchester United at an FA Cup match against West Ham Utd. Sapphire walked out holding hands with Manchester United team captain, Ryan Giggs. She has also attended many events where she has been able to talk to celebrities about the importance of joining the Blood, Organ and Bone Marrow Register to help save lives.

Just recently she attended PR Guru Max Clifford's charity event at The Dorchester Hotel in London where she met and talked to a lot of celebrities including Simon Cowell & the Duchess of York, Sarah Ferguson.

Sapphire is at a performing arts high school and loves piano, drama and vocals

lessons and hopes to go to the BRIT school to complete years 10 & 11. Her aim is to become a playwright and composer.

You can see that Sapphire is truly an inspirational young girl and was awarded a Certificate of Achievement from our Chair at our Christmas party in December 2012. Sapphire has also raised lots of money from sponsorship at our annual fundraising walk, which takes place every June in Crystal Palace park. Well done Sapphire!

Sincere thanks and appreciation to the Manager, Mrs Sherill Gregory and her team of Specialist Nurses at Croydon Sickle Cell Centre. Their love, passion, dedication and professionalism to Sapphire and other sickle cell sufferers in Croydon makes the Support Group such a success in managing the disease for all their patients.

Alice Allison (Chair)

RESEARCH UPDATE



Professor Swee Lay Thein
Consultant Haematologist, King's College Hospital and Professor of Molecular Haematology, King's College London

UPDATE ON CLINICAL STUDIES

1. Genetic modifiers of sickle cell disease

Chief Investigator – Prof. S L Thein

We are recruiting for research participants at the following centres taking part in this study: King's College; Guy's & St. Thomas'; Queen Elizabeth, Woolwich; and Lewisham Hospitals.

2. MP4CO (a modified haemoglobin product) for treating sickle cell crises

Chief Investigators – Prof. S L Thein & Dr Jo Howard

The Phase 1 safety study has now been completed and has shown that MP4CO has little adverse effects. The next phase of the study is due to start in summer 2013.

WOULD YOU LIKE TO GET INVOLVED?

We are recruiting for volunteers for both studies. Please speak to your clinician or clinical nurse specialist if you interested in taking part.

A big thank you to you to all the patients who have volunteered these studies so far.

HEALTH PSYCHOLOGY SERVICES

EVENTS AT THE EVELINA CHILDREN'S HOSPITAL

HALF-TERM CHILDREN & PARENT'S GROUP

In February half-term, the Evelina Children's Hospital hosted a children's group for 10-14 year olds and a parent's coffee morning where families were invited to share their 'top tips and tricks' for coping with sickle cell disease

On a sunny winter's morning, the Atrium at the Evelina was filled with 30 children and siblings, and their parents (photo, right).

We had a group discussion where families shared their biggest fears and worries about living with SCD. Children reported feeling reassured that there were others who shared the same worries as themselves. Families then had the opportunity to share their expert knowledge on living with SCD. While parents continued their discussions over coffee, the children were invited to draw or write down their top tips which were so fantastic, we are hoping to develop them into a resource to be used in our service.



We will soon be sending out more information for the next Evelina children's group to be held in the Summer half term on Thursday 30th May. It would be great to see as many families as possible.

If you have any questions about the Evelina Sickle Children's Group or would be interested in coming to the next one, please contact Florence via email: florence.bristow@gstn.nhs.uk or phone: 0207 188 7774.

CHILDREN'S CHRISTMAS PARTY 2012

In December 2012, the Evelina Hospital held its annual Christmas party.

And some of our young sickle cell patients had great fun meeting Father Christmas and enjoying all the activities, food and fun on offer.



With thanks to our supporters:

