Issue 13 December 2019

KING'S HEALTH PARTNERS

Pioneering better health for all

Red Cell Newsletter

A newsletter for patients with sickle cell

South Thames Sickle Cell & Thalassaemia Network

Hello and welcome to the latest edition of the Red Cell Newsletter (issue 13). We hope you enjoyed reading our previous edition, issue 12 with articles such as: **Meeting the consultants, Patient story (Living with sickle cell) & International thalassaemia day.** If you had missed any issue then you can find a copy online **(www.ststn.co.uk).**

In this edition, we have more informative articles for you including barriers and enablers to employment with sickle cell disorder.

We hope you enjoy this edition and welcome your contributions and feedback, so please do get in touch!

Daud Daud
STSTN Network Manager

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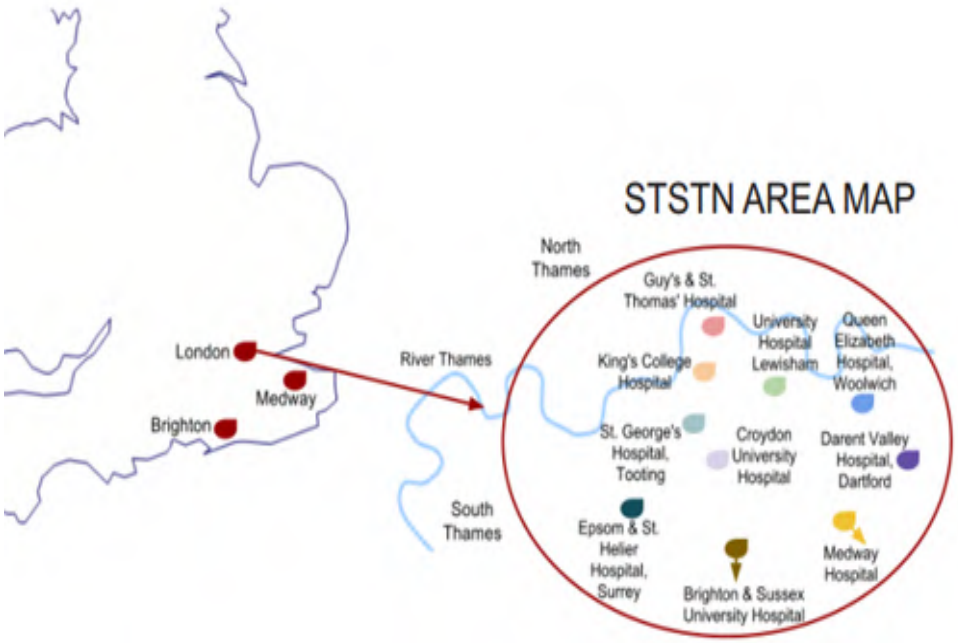
@STSTNetwork

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

For more information visit: www.ststn.co.uk

Barriers and Enablers to Employment

Between 2018 and 2020 this partnership between De Montfort University, the Sickle Cell Society and OSCAR Sandwell, conducted two focus groups and interviewed 47 adults living with sickle cell disease (SCD) in London, the Midlands and the North of England about their experiences in work and employment.

In this study, the majority of people with SCD either were, or had recently been, in paid employment. This included a lawyer, teacher, nurse, entrepreneur, engineer, laboratory scientist, pharmacist, driving instructor, actor, sales manager, administrator, events manager, care home owner, bank clerk, factory worker, cleaner, transport worker, youth worker, community worker, fashion model and musician.

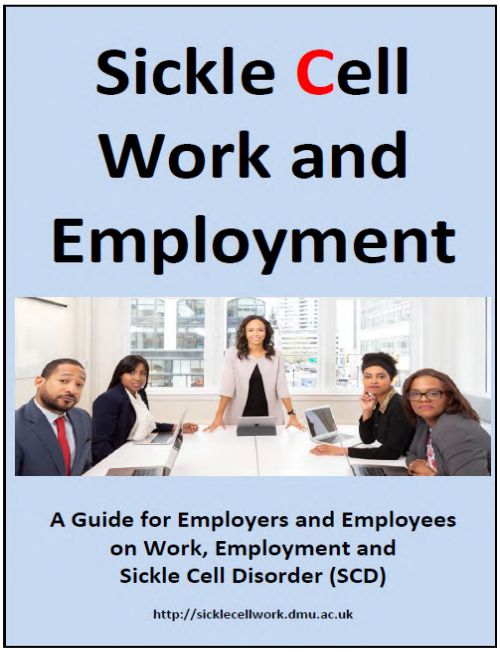
However, work is a much broader concept than just paid employment. Not all work is recognized as such, nor is it necessarily paid. For example, many women with SCD undertake care work in raising children—the next generation who contribute to society through their work. In our study some men with SCD who have not been able to stay in paid employment have taken on the role of main care provider in the home. This is work for the overall benefit of society, even if it is unpaid.

Undertaking unpaid care work, whether of children, older relatives or disabled family members is not only undertaking socially useful work, but may be enabling someone else in the household to take up paid employment. These are indirect contributions to the economy.

In this study, many people with SCD also carried out important voluntary and community work. This included running youth clubs; taking Sunday school or other supplementary education classes; undertaking work for non-SCD charities; offering financial and social support to others living with SCD; raising funds for, preparing and distributing baby packs for mothers of newborn babies with SCD; running education sessions on SCD for NHS staff; and liaising with schools, employers or housing agencies in order to ensure best support for those living with SCD. As well as being valuable activities in their own right, these activities contribute to the creation of good citizens, improving overall education levels in the community or reducing crime and anti-social behaviour, for example. In some instances this work also helps reduce costs associated with treatment of SCD: giving doctors and nurses a better understanding of SCD or ensuring that schools and employers do not damage the health of someone with SCD and cause them to require unnecessary treatment.

Some work of doctors and nurses improves the capacity of people living with SCD to manage their own health and reduce their need for treatment. However the people who undertake the majority of this precautionary and preventive health work are people living with SCD themselves. In this study, people with SCD managed their lives in terms of self-denial, restricting amount and range of leisure activities in order to remain healthy for work and stay out of hospital. This self-management improves their health status and both directly, by reducing their use of health services, and indirectly by enabling them to earn money and improve their standard of living and capacity to remain well. Even those living with SCD who were most ill themselves contributed through activities such as hospital visiting, community activities, fund-raising for support groups and social support for others with SCD.

On the basis of the interviews and following two policy development workshops (one in the West Midlands, one in London) with the 47 adults living with SCD, a team comprising university researchers (Simon Dyson and Maria Berghs) and people living with SCD (Vanetta Morrison and Kalpna Sokhal) produced a Guide to Sickle Cell Work and Employment.



This is available to download from the project website (http://sicklecellwork.dmu.ac.uk) and hard copies and presentations on the research can be requested from the project team (Contact: sdyson@dmu.ac.uk or maria.berghs@dmu.ac.uk).

SICKLE CELL SOCIETY

DE MONTFORT UNIVERSITY LEICESTER

BIG LOTTERY FUND
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drill
Disability Research on Independent Living & Learning

ORGANISATION FOR SICKLE CELL ANAEMIA RESEARCH
OSCAR Sandwell

National Thalassaemia Day (UK)

The United Kingdom Thalassaemia Society (UKTS) launched their National Thalassaemia Day (UK) on 19th October 2019. This date was chosen to mark the 10-year anniversary of the passing of Costas Kountourou, a prominent figure in the world of thalassaemia.

On this date, the charity opened its doors to the general public, inviting everyone to walk in and be tested for thalassaemia and other conditions.

During the day UKTS:

- **Offered free screening to the general public for thalassaemia and sickle cell trait**
- **Offered counselling and guidance (for positive test results)**
- **Partnered with NHSBT for "know your type" blood testing / promote the need for blood donation**
- **Offered free screening for Hepatitis C and other infected diseases**

The society extended an invitation to all interested to join them on the 19th October 2019 as this was a major awareness-raising event. Given that there are over 300,000 carriers of thalassaemia in the United Kingdom and that it is a hereditary condition, clearly there are many members of the public who could benefit from thalassemia screening.

Thalassaemia is a chronic genetic blood disorder affecting the genes that are responsible for production of red blood cells. What this means is that patients with thalassaemia are dependent on regular blood transfusions throughout their lives. Without them, they would die in early childhood. Thalassaemia developed as an evolutionary response to malaria which is why it mainly affects those coming from regions such as Asia and South East Asia, the Mediterranean, South America, the Caribbean, Northern and Central Africa and the Middle East. Whilst it was initially prevalent in these regions, due to the migration of communities over the centuries, anyone can be at risk. In fact, 10,000 babies are born with thalassaemia every year. This is why it is so important to be screened.

In the UK, women are typically offered screening after they become pregnant despite it being available to everyone at any point in time. The blood test is usually done between 8-10 weeks. If the expectant mother has a positive result, the father of the baby is then screened. This process can sometimes, despite the best efforts by the NHS team, take the pregnancy up to 16 weeks, at which point it many couples will be understandably reluctant to terminate a pregnancy.

The event was formally opened by the Executive Director Romaine Maharaj, Chair Gabriel Theophanous, Treasurer Oddy Cooper, Patrons Peter Polycarpou and Kypros Kyprianou, volunteers and staff. Other prominent attendees were the Mayor of Enfield Kate Analou, MP for Enfield Bambos Charalambous, David Burrowes (Tory representative for Enfield), doctors, nurses and members of the public.

Support for testing were provided by the North Middlesex Hospital (led by Liz Odeh), NHSBT (led by Nneka Ofoche), Hepatitis C and other infectious diseases (led by Dr Indrajit Ghosh). The event was also supported by a brilliant team from the Infected Blood Inquiry.

The event ended with a small private function to celebrate the life of Costas Kountourou, a patient who worked tirelessly to help improve the care and lives of patients internationally.

www.ukts.org

60 WITH SICKLE CELL

Two days before my 30th birthday I had the worse pain ever in my chest. The ambulance took me to a hospital. Once there, they diagnosed pneumonia. They incorrectly calculated the dosage of pethidine that they put in the pump and this led to me being overdosed. First one lung collapsed, I was rushed to the Intensive Care Unit where eventually both of my lungs collapsed. I was still in a coma after five days and had to have a tracheotomy. The doctors informed my family that there was nothing more they could do but stated "she is fighting".

When my 60th birthday was approaching earlier this year I was in such a state of apprehension, especially after the 30th birthday episode, that it wore me out. Making myself ill with worrying "was I going to make it to the day?" I was unable to plan the 60th party that everyone was expecting me to have because I just didn't have it in me to plan it.

The red team, as usual, were very understanding and told me there was no reason for me to think that I wouldn't make it to the age of sixty. I have only ever seen about two people in our clinic that were over sixty.

When the day arrived it was a Sunday. I was overjoyed. I took my children with me to church as a form of thanksgiving for the extension of my life. I still pinch myself now to know that I have reached this milestone.

When you make plans for the future it is with trepidation. There is always this fear in the back of your mind of "will I make it?"

I love helping the Red Team on our monthly support meetings, even though it is a small amount of help. I also make a monthly donation to the Research Of Sickle Cell. The research team do still require financial help as they don't receive the same amount of support that the other blood related disease get. It's my little way of giving back something to the hospital that has done so much for me over the years and I would encourage others who are able to do so to do the same.

If we do not support research into improving our lives, then who will?

Turning sixty has taught me to live my life to the fullest, love the people around me, pay less notice to the worries, dance, laugh, sing and be very, very happy. Also to keep looking great for the younger ones that are following us, so that they can see you can make it to 60 and still look good with it.

Elaine Leachman-Quamina

CROYDON SICKLE CELL & THALASSAEMIA SUPPORT GROUP

The idea of a support group originally came from haematologist and nurses working at the Mayday Hospital in the 1980s. They saw the need to help improve the everyday lives of people living with Sickle cell and their families. The group's mission statement was 'a helping hand is sometimes all that is needed.' That 'helping hand' has been provided by Annie Mc Donald, the group's secretary and her team since the group was set up. Annie had a working life and brought up her own family and herself has sickle cell. She is especially trusted and valued by the users of the group.

The Support Group office is housed in the Croydon Sickle Cell Centre which is about a mile from Croydon University Hospital. This space is shared with the Specialist Sickle cell nurses from the hospital. This shared space helps to forge close links between the nurses, the support group and those with sickle cell using the centre. For example, mothers who have a baby, recently diagnosed with sickle cell, are given a 'welcome pack' with baby clothes, and each month the mothers and their toddler's meet at the centre. This meeting is run by a specialist nurse but a support group committee member, with sickle cell disorder, attends. This helps mothers see first-hand how others can live full lives with sickle cell. When people are admitted to Croydon University Hospital they are visited by arrangement with the specialist nurse, (and the patient's permission) and given a toiletry hospital pack, fruit and some company too!

To raise funds, a sponsored walk is held each year. Some of the money raised this year went on an exciting trip to Longleat Safari Park! This was enjoyed by children with sickle cell and their families together with adults with sickle cell, including the oldest resident in Croydon with sickle who is in her eighties!

These activities mean the group continues to provide a trusted 'helping hand' and some fun to all ages by working closely with the specialist nurses, and people sickle and their families.

https://www.cscatsg.org

Croydon
Sickle Cell & Thalassemia
Support Group

New professors appointed

In September 2019, King's College London promoted four doctors with an interest in Sickle Cell Disease (SCD) to become professors. This not only recognises the individuals for their contribution to Sickle Cell Disease clinical services and research but also emphasises the importance of Sickle Cell Disease within King's College London.

Jo Howard, lead of the adult haemoglobinopathies service at Guy's and St Thomas' was made Professor of Haemoglobinopathies. Jo is lead of the STSTN and chair of the Clinical Reference Group for Haemoglobinopathies. Her research interests include the natural history and chronic complications of SCD and she has led several clinical trials investigating new treatments for the management of SCD in adults.

Baba Inusa is lead of paediatric sickle service at Evelina Children's Hospital and is now Professor of Paediatric Haematology. Among other research projects, Baba is lead of the African Research and Innovative Initiative for Sickle Cell Education (ARISE), an EU funded project to create a consortium for researchers across the EU, Africa, Lebanon and the USA to provide an international network to better understand and treat sickle cell disease, his research interest includes newborn screening and the study of risk factors for renal impairment and stroke in children with SCD.

Eugene Oteng-Ntim is consultant obstetrician and gynaecologist at Guy's and St Thomas' and is now Professor of Obstetrics and gynaecology. He has run the sickle obstetric service for over a decade, has produced national guidelines on the management of sickle pregnancy and his research includes a national survey into the outcomes of pregnancy in women with SCD, the development of non-invasive pre-natal testing and running a national trial investigating the role of transfusion during pregnancy in women with SCD.

Claire Sharpe is an honorary renal consultant at King's College Hospital and is now Professor of renal medicine. In addition to her research interest in cell signalling in renal fibrosis, she has a clinical and research interest in the pathophysiology and management of patients with the renal complications of SCD. She has run the sickle-renal clinic at King's College Hospital over the last decade and has published the outcomes of this clinic and guidance on how to manage the renal complications of SCD.

Baba and Jo gave their inaugural lectures in September 2019 as part of a series of lectures presented by King's College London and chaired by Professor Richard Trembath, the Executive Dean of the Faculty of Life Sciences and Medicine. Baba's lecture was entitled 'A multi-dimensional approach to sickle cell disease' and was introduced by Professor David Edwards, Director of the Institute for Women and Children's Health. Baba spoke about his career from training in Nigeria, his early work in the UK, the development of paediatric sickle services and the important work in leading the collaboration with American Society of Hematology, Royal College of Pathology and the British of Haematology in strengthening health systems for the management of SCD in Africa.

Jo's lecture was entitled 'Improving sickle cell outcomes from the capital to the country' and was introduced by Professor Anne Greenough, Professor of Neonatology and Director of Education and Training. Jo discussed her haematology training and mentors, the development of adult service at GSTT, including the development of the multidisciplinary team and the STSTN and the development of national guidelines and the peer review programme. She also discussed new research in SCD including the work on voxelotor a new drug being developed in trials at KCL.

The talks were well attended by family, friends, colleagues and students and were followed by a social gathering.

Eugene and Claire are due to give their inaugural lectures during 2020 and we hope that STSTN colleagues will attend. There will also be an educational day 'A celebration of Sickle Cell Disease care in South East England; looking forward to the next decade' on Wednesday 22nd January 2020 featuring all of our new professors as well as Professors David Rees and John Strouboulis from King's College London.

Professor Jo Howard & Professor Baba Inusa, GSTT

Professor Claire Sharp, KCH

Professor Eugene Oteng-Ntim, GSTT

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.

Visit patient zone on our website (www.ststn.co.uk) to find patient information, clinic times, support group information and previous editions of the red cell newsletters.

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.

*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

SICKLE CELL SOCIETY

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: King's College Hospital 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