sicklecell

SICKLE CELL SOCIETY

THE NEWSLETTER OF THE SICKLE CELL SOCIETY

SPRING 2019

In this issue:

Celebrating 40 Years of the Sickle Cell Society

I'm In Crisis – A New Report

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Plus, so much more…

www.sicklecellsociety.org

SICKLE CELL SOCIETY Celebrating 40 YEARS 1979 - 2019

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Sickle Cell Society Newsletter Spring 2019

Introduction

2019 marks the 40th Anniversary of the Sickle Cell Society. We are so excited to have reached this milestone and are looking forward to celebrating with you. Our Autumn newsletter will be a 40th Anniversary special and will have more information and articles about the work we have been doing for the last 40 years. In this newsletter you can read about some of our plans for celebrating and how you can get involved, including information on our 40th Anniversary Gala Ball.

The Sickle Cell Service Review has continued to be a focus of the Society. Commissioned by NHS England, working with the Clinical Reference Group for Haemoglobinopathies and the Sickle Cell Society, the review looks a haemoglobinopathy services, particularly how short and long stay admissions to hospital is provided. In our previous newsletter we talked about the analysing our findings. We have now done so and have presented our report to NHS England and they have responded. You can read more about it later on in the newsletter.

In August, we took 30 children on our annual children's holiday. Always a highlight of the year, the children's holiday this year saw the kids engaged in a range of adventure activities from zip lining to archery and included time teaching the children how to better manage living with sickle cell. As well as the children's holiday there have also been a whole range of great activities each month for children and young people to get involved with.

In November, as part of the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG) we launched "I'm in Crisis" a report into the lack of representation of sickle cell and thalassaemia in the education of pre-registration nurses and midwives. This was the second report we have launched since we became secretariat for the SCTAPPG jointly with UK Thalassaemia Society. The launch saw talks from Dr Lola Oni OBE, Chair of the Nurses Education Advisory Group and Service Director of Sickle Cell & Thalassaemia Centre Central Middlesex Hospital London and Michelle Ellis, Senior Lecturer of Child Health at City University London. We hope that this report will lead to the inclusion of sickle cell and thalassaemia in the national curriculum and that we will see improved patient care and more trainee nurses in haemoglobinopathies.

The APPG report is not the only thing to be published, John has also co-authored two publications. One focuses on the role of patient organisations in delivering health services and the other on sickle cell newborn screenings across Europe. We are excited to collaborate with professionals from around the world and look forward to see this continue.

The Sickle Cell and Thalassaemia Screening Programme has also been a high priority for us as our contract with NHS England came to an end. We are passionate about the programme and the work we have done so far so, in partnership with the UK Thalassaemia Society, we applied and won the new tender. We will now continue the great work which has been done so far and develop it further.

Sickle cell has also been in the mainstream as we are sure that you saw the inclusion of a sickle cell story line in BBC One's 'Call the Midwife'. We were delighted to have sickle cell brought to a national audience in a moving and authentic way and hope that this awareness will continue.

We built on this national interest in sickle cell when our patron, Professor Dame Elizabeth Anionwu, was invited to take over the @NHS twitter account for a week in February. With almost 40,000 followers, the NHS account allowed Elizabeth to inform and educate a wide audience about sickle cell and the work we are doing.

As we celebrate our 40th year we hope the achievements you can read about in this newsletter will continue and the next 40 years will be full of exciting developments for people living with sickle cell.

John James OBE Chief Executive *and*
Kye Gbangbola Chair of Trustees

Celebrating 40 years of the Sickle Cell Society

The Sickle Cell Society is turning 40! To celebrate our 40th year we are running a whole host of events and activities and we would love for you to celebrate with us and get involved. We have dedicated a section of our website to our anniversary as a central hub for all the news and information on the events we will be running. You can keep up-to-date here: **www.sicklecellsociety.org/scs40/**

Keep an eye out for our special 40th Anniversary Logo on our website and flyers for things we are involved with.

Dates for the Diary

Sheffield Patient Education Day

Working alongside the South Yorkshire Sickle Cell Organisation (SYSCO) we will be running a patient education day in Sheffield. The day will focus on a range of topics including: clinical trials, the Sickle Cell Service Review, paediatric care and wider social support. The day will kick off with lunch and will include time for a Q and A on each of the topics.

Date: 21/06/19
Time: 12:00-16:30
Location: Sheffield

Make sure you are following us on social media and are a member to be the first to hear about when you can book your free place

Thanksgiving Service

Come together and give thanks for the sickle cell community and for the strength and kindness of patients and carers at our Annual Thanksgiving Service.

Date: 23/06/19
Location: St Mark's Church, Kennington

AGM

Our Annual General Meetings are always popular and are a great way to find out about all about the work we do. There is also plenty of opportunity for you to have your say and we also include an education day on a specific topic. Last year we looked into sickle cell and mentoring. This year our focus will be celebrating 40 years.

Date: 20/07/19
Time: All Day
Location: De Vere Grand Connaught Rooms, Central London

Keep an eye out on social media and at **www.sicklecellsociety.org/agm19/** for when you can book your free place.

40th Anniversary Gala Ball

We are so excited to be celebrating 40 years and want to celebrate in style. The 40th Anniversary Gala Ball is an event not to be missed. Held at the Royal National Hotel in Central London, the Gala Ball will be an evening of dinner, dancing and entertainment.

Date: 14/09/19
Time: Evening
Location: The Royal National Hotel, Central London

Make sure you sign-up to be a member to be the first to hear about when tickets are on sale. Also follow us on social media: @SickleCellUK (Facebook, Twitter, and Instagram) for all the latest updates).

Plus, more events to come, including a celebration event in Birmingham, plus guest blogs, a special edition 40th Anniversary newsletter and other ways for you to get involved.

We hope to be able to celebrate with you at one of our events and throughout the rest of the year.

Sickle Cell Service Review

You Spoke We Listened
This information responds to the Sickle Cell Service Review

Over the past year we have been updating you about NHS England's Haemoglobinopathy Review - a series of changes planned for how short and long stay hospital care for people with Sickle Cell Disease (SCD) is arranged. The Sickle Cell Society wanted to ensure that the opinions and experiences of people with SCD were taken into account by NHS England (NHSE) when making the changes, and so we ran a series of engagement activities designed to gather your feedback. During the process, we heard from more than 300 people, collated a report on our findings and presented our learning to senior NHS representatives.

What are the changes?

Most immediately, NHSE will introduce 10 new 'Haemoglobinopathy Coordinating Centres' or 'HCCs' across England, which will take responsibility for leadership and education on sickle cell care within their geographical areas. NHSE anticipate having this new model in place by Spring 2019.

In the future, they also plan to develop a National Haemoglobinopathy Panel to review the care of people with the most complex needs and oversee the introduction of new treatments as they become available.

They will also review and expand how the National Haemoglobinopathy Register, which records the numbers of people with SCD, is used, with a view to making it a more effective tool to monitor treatment and outcomes for sickle cell patients.

What did we find?

Our respondents broadly supported the above plans, however they repeatedly emphasized that the voices of people affected by sickle cell must be genuinely represented throughout the change process, to ensure that better patient care is achieved.

We also heard about a range of general concerns about the quality and variation in sickle cell care that were not directly related to the review, this included treatment received in A&E, levels of community support available, and concerns about the expense of prescription charges.

What did our engagement process achieve?

Following your feedback, we agreed with NHSE that:
Specific patient questions, derived from our findings, will be asked of potential HCC suppliers in the HCC procurement process

As HCC's develop, they will continue to involve patients and also monitor how HCCs positively impact upon the transition of people, both across care settings and from paediatric to adult services

HCC's will report on their progress annually, documenting how they have influenced the quality of patient treatment and care

That the Sickle Cell Society and NHSE will work together on further engagement methods to ensure continued patient engagement in all of the new arrangements.

Where can I find more information?

NHSE have provided us with a written response to our engagement findings, which also covers the concerns raised that are not addressed by their review. You can find that here www.sicklecellsociety.org/servicereview

The Sickle Cell Society have also published a series of updates and responses to the topics raised by this engagement work, look out for this logo on our website.

We will keep you updated about future developments and ways in which you can get involved in the ongoing monitoring of the NHSE's changes. If you have a question or comment about this work, please contact us at: info@sicklecellsociety.org.uk You can also stay updated by visiting: www.sicklecellsociety.org/servicereview

A Small Window into a Mother's World

I don't know how you cope; I don't think I could do it. I just wouldn't survive it.

I have heard these sentiments in various compositions and every time I hear it, I feel angrier than the last time. I am sure most of those who have said it to me mean well and sometimes it comes from their own fear and secret joy that they do not have this particular challenge in their lives; I get that, because I have also had similar feelings about other situations. However what infuriates me is the lack of sensitivity that accompanies those sentiments, it suggests you have a choice in the matter. I usually retort with righteous indignation saying,' so if I couldn't or didn't cope, what exactly would that look like? Would I give up my child, run away, pull the covers over my head, what exactly do you think I would do?

My too cute for words first born child was born in Atlanta GA USA and I could hardly contain my joy when she arrived. She had eyes the size of saucepans and her cheeks, well they were the biggest, roundest, juiciest things you had ever seen. I spent half the time in hospital with her fending off the nurses who kept trying to kiss her cheeks! Then we got the news that she had sickle cell. She still looked as angelic and as beautiful as ever, so I didn't know what this illness meant. My only understanding of the condition was that it was something to be feared and not talked about. I had a cousin in Nigeria who was a lawyer, who had lived with the condition but lost her battle some years earlier. As close as I was to her and as much as I adored her, we never discussed her illness. I come from a community and society that has deep rooted cultural and societal fears around disability and most serious ailments. If you talk about it you might somehow be inflicted by it or it might have been a curse or punishment and the usual pulp and dribble that accompany ignorance and fear.

Gloria and Daughter

My daughter turned thirty this year (unbelievable!) She's smart, funny, creative, a kind, generous soul. From the day she was born I was told she was my spitting image. Thirty years later people still call her my mini me…totally freaks us both out! She has struggled and continues to, sometimes barely having much left in her due to her determination and choice to live. It was hard going through her education. She went to take her A levels just a few hours after being discharged from a hospital stay, and did quite well.

We have a particularly symbiotic connection, where if she itches I scratch. I will get an inkling something isn't right and send a message to her and she will call me a witch, asking how I knew! Or she will seek me out because she senses I may be going through something. We have been doing this for forever.

I will never, ever get used to seeing her in pain! I will always want to find a way to make it go away. She usually smiles and looks at me with equal measure of kindness and pain when she sees me running helter skelter, trying to find a solution to a particularly severe crisis. However, what she has brought to my life, her younger sisters' life, to our family as a whole has been beyond description. The only words that come to mind are exquisite joy! Her ability and capacity to draw from the depth of her soul while struggling; the empathy, love and attention that her family require confound me. She once described me as her lucky charm, her protector. In my mind I felt if I were any of those things she would be without sickle cell. But that's not how it works is it?

Yes, there are very dark moments for her and our family from time to time, but she thrives in much deeper ways in spite and because of her challenges. She is a singer, song writer, she plays in a band, has a wicked dry sense of humour, the sound of her laughter is so rich and melodic and joyful, it moves me every time. She is living her life on her own terms. As much as she feels despairing at times, she's the definition of an optimist. I don't know what's ahead for her, but we all have that in common. My mantras, affirmations, even clichés have always included the following: Tomorrow is another day, no condition is permanent no matter how dire, everything must change, nothing stays the same. The future is a mystery to all of us; we are all in the dark about that, it's an unknown quantity. We only have the gift of today which is why it's called the present!

By Gloria Ogunbadejo
Helpline and Information Officer

Infected Blood Inquiry

Do you know about this Inquiry?

The Inquiry will examine how (particularly in the 1970s and 1980s) men, women and children in the UK were given infected blood and/or infected blood products; the impact on their families; how the authorities (including government) responded; the nature of any support provided following infection; questions of consent; and whether there was a cover-up.

Blood transfusions in the 1970s and 80s carried a small risk of infection from Hepatitis C and other viruses. The risk was significantly reduced from 1991 onwards when blood donations were routinely tested and screened for the virus.

If you received a blood transfusion during the 1970s and 1980s, you may be at risk and we would strongly recommend you **request a test for infection (in particular a test for Hepatitis C) from your GP or other relevant services**.

If you have been affected, you may also be entitled to financial support.

You could be eligible for **lump sum payments of up to £70,000**, in addition to regular monthly payments.

Everyone infected and affected by the Infected Blood Scandal has a story to tell. Inquiry Chairman, Sir Brian Langstaff said:

"Every voice is valuable, we want to hear from everyone." The Public Inquiry needs to hear as many stories as possible, fitting each one together like pieces of a jigsaw to build a full picture of what happened, why and what was the impact.

If you would like to share your story with the Inquiry, or would simply like to find out more, please contact Ms Rochelle Powell, who is liaising with the Society. Her details are below:

Rochelle Powell
Paralegal, Infected Blood Inquiry
Mobile: **07743 600 832**
Address: Fleetbank House, 1st Floor,
2-6 Salisbury Square, London, EC4Y 8AE
Email: rochelle.powell@infectedbloodinquiry.org.uk

You can also get support and advice from our **Helpline Team** by calling **020 8963 7794** or emailing: **helpline@sicklecellsociety.org**

The Inquiry begins hearing individual testimony at the end of April 2019. These hearings will take place over 11 weeks spread over May, June, July and October, across the UK. If you are interested, it will be possible to register to attend these hearings. More details are available here on the Inquiry's website: **https://www.infectedbloodinquiry.org.uk/**

Nothing in or about the Inquiry should deter individuals from being donors. The Sickle Cell Society and NHS Blood and Transplant very much want existing donors continuing to give the gift of life.

[1] The Penrose Inquiry estimated that the prevalence of Hepatitis C amongst the UK population from 1982 to 1984 was between 0.6% and 1%. The Inquiry will be looking afresh at these estimates to produce its own figures.

The Societies are engaged again!

The Good News

If you are an ardent reader of our Sickle Cell Society newsletters (well the bit where I update you on screening!) you might recall that in April 2016 the NHS Sickle Cell and Thalassaemia Screening Programme ('Screening Programme') commissioned and began a two year project in collaboration with the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS). This 'Engagement Project' was to investigate barriers affecting the timeliness of the offers of screening and Prenatal Diagnosis (PND) so we could determine ways of improving services. At the end of what was a successful collaboration, the Screening Programme published a new tender in June 2018 for further work. This tender outlined the challenges the Programme was still facing and needed support with. Once again a collaborative approach was needed to understand the reasons for variation in performance by screening providers and ways to improve performance. Engagement and outreach was also essential to ensure that screening service provision continues to be underpinned by service user needs. Well, the good news is that the Sickle Cell Society and UK Thalassaemia Society bid for the new tender and won, so we must have been doing something right! Our new contract officially started in August 2018 and I will be working to deliver the project with Romaine Maharaj from the UKTS (since Elaine Miller has now left). The tender is expected to be for a period of 3-5 years.

By Iyamide Thomas, NHS Engagement Lead, Sickle Cell Society

Photo: Rowena Maharaj

Iyamide and Romaine run a joint stall at an International Sickle Cell and Thalassaemia conference in London

What's Involved

The work priorities for each year will be defined at the start and in Year 1 (i.e. August 2018 to July 2019) these are:

Review and update the *'Sickle cell disease in childhood: standards and guidelines for clinical care'* publication which was last updated in October 2010. Some of you might recall the new and updated adult standards of care for sickle cell being launched in the House of Commons in May 2018.

Updating *'A parent's guide to managing sickle cell disease'* a book which parents are given especially when they have just had a child with sickle cell. Parents find this book very useful and some carers have said:

"It helps us to understand the condition better"
"I was afraid but after I read the book, I said ok people are managing it so why don't I"
It gives you guidelines on what to do if you are conversant with it, it reminds you to check baby's temperature"

We will be implementing the findings from the previous year which in this case is supporting the actions and recommendations from our *'Parents' Stories'* publication we produced, which documented people's personal experiences of the Screening Programme. The Parents Stories raised a number of issues for the public- which is for you all to present early in pregnancy and that you can contact maternity and specialist NHS sickle cell and thalassaemia screening centres direct when you are pregnant and not just your GP. This is important particularly if you and your partner are carriers of a sickle cell or thalassaemia gene, when you are known as an 'at-risk' couple. Screening health professionals should provide direct access to specialist sickle cell and thalassaemia nurse counsellors to known 'at-risk' couples where available.

Another work priority this year is for us to Support the Screening Programme in its **Newborn Outcomes System (NOS)** which is an automated system that supports the referral of babies diagnosed with sickle cell into treatment. The NOS also links to the National Haemoglobinopathy Register (NHR) a confidential database of patients with mainly sickle cell disease and thalassaemia major living in the UK. Our work to support the NOS will be to raise awareness of the system (starting with this newsletter article!) and help families affected by sickle cell to improve their understanding of why data is needed and trust the collection of data both in the case of newborns and also people already living with sickle cell.

It is important for individuals with sickle cell and thalassaemia to agree for their clinician to register them on the NHR as information obtained from the NHR helps to secure funds to develop improvements in treatment and patient care in your treatment centre. The information is also essential for healthcare planning, identifying patient numbers and research into improved treatment.

So as you can see Romaine and I have a lot to be getting on with in this first year! Some of our work will involve running focus groups with parents, carers and people affected by sickle cell or thalassaemia so we can get your input. We hope you will agree to help and be part of any feedback we require as only then can we continue to ensure that the NHS Sickle Cell and Thalassaemia Screening Programme and other related service provision is really underpinned by service user needs.

Our newest trustees – one year on

Our trustees are dedicated volunteers tasked with the ultimate responsibility for governing the Society. They do an excellent job of making sure the Society can continue to grow and they work alongside staff to ensure that the Society remains service user focused.

Our newest trustees are Joy Adeyemo and Dr Josephine Ruwende who both joined in April 2018.

Joy Adeyemo

Joy is a highly experienced professional in the field of politics with specialisms in casework and community engagement. Having graduated with a degree in Politics and International Studies, Joy has gone onto work in Westminster and London's City Hall supporting the work of high profile politicians. She has lived experience of Sickle cell disease and is an avid champion of improved services, awareness and advocacy for the disease and those who live with it.

Dr Josephine Ruwende

Josephine is a Public health doctor working as a clinical advisor and cancer screening lead for NHS England (London) and Public Health England. Jo did her undergraduate medical training in Zimbabwe and her specialist public health training in London and East Anglia. She has many years of experience in international development, having worked for organisations such as the United Nations, Swedish International Development Agency and the Department for International Development. Before joining the Sickle Cell Society Board, Jo was a trustee for the AMREF-UK, which is an international health charity working across Africa. Jo has close to twenty years of experience supporting the NHS deliver high quality services that address patient needs, are evidence-based and provide value for money.

Prescription Payment Petition

A new petition has been launched to "Provide prescription payment exemption for people with Sickle Cell Anaemia." The petition aims for prescription charges to be discussed in Parliament and for an exemption to be made for people living with sickle cell anaemia.

The petition was created by Amoafi Kwapong on the UK Government and Parliament Petition website. The petition reached 10,000 signatures and received a response from the government:

"There are no plans to review the list of medical exemptions from NHS prescription charges. However, extensive arrangements are already in place to ensure people can access affordable prescriptions."

We are disappointed with the Government's response to this petition and will increase our efforts with our members and the Prescription Charges Coalition to ensure prescription charges for sickle cell are scrapped. The petition is open until 18th April 2019 and at 100,000 signatures, this petition will be considered for debate in Parliament.

You can read the full Government statement and sign the petition at: **tinyurl.com/petitionSCD**

You can find out more about the work of the Prescription Charges Coalition at: **www.prescriptionchargescoalition.org.uk/**

Children's Activities

As you know, for the past 2 years, we have offered a wide range of exciting and enriching children's activities for children affected by Sickle Cell. This has been a very successful and positive programme which has been well attended and received.

Unfortunately, our funding for this programme of activities from BBC Children in Need is ending on the 31 March 2019. We are of course seeking alternative sources of funding that will allow us to offer further activities, but until then we will no longer be able to provide children's activities after 31st March this year.

We will of course still be running our annual children's holiday in August. In addition, this year is the Sickle Cell Society's 40th Anniversary, and we will be running various celebratory events throughout the year to commemorate this. We hope you will support us in this (find out more at **www.sicklecellsociety.org/scs40/**).

We will keep you informed of all the activities and events that we will be running this year, and hope that you will continue to support the Society as you have been doing.

Please check our website regularly for updates and events that will be taking place during the year.

We would like to thank all children and their parents/carers, volunteers and volunteer parents who have supported and participated in the children's activity programme.

By **Grace Adejowun** Children's Activity Leader

I'M IN CRISIS – A REPORT

New Report Published on the Lack of Representation that Sickle Cell Disease and Thalassaemia has in Pre-Registration Nurse and Midwife Education

Outside the Houses of Parliament

Dr Lola Oni OBE

The All-Party Parliamentary Group for Sickle Cell and Thalassaemia (SCTAPPG), chaired by the Rt Hon Diane Abbott MP, launches report into the lack of representation of sickle cell and thalassaemia in the education of pre-registration nurses and midwives.

On the 20th November the SCTAPPG, chaired by the Rt Hon Diane Abbott MP, met in parliament to launch a new report "I'm in Crisis" which surveyed 197 students from nine nursing and midwifery schools and faculties. The report was launched following anecdotal reports that qualified nurses, midwives, doctors and other health care professionals lack knowledge of sickle cell and thalassaemia and that this affects their ability to provide skilled and effective care for those with and at risk of these life-long genetic, chronic and potentially fatal conditions.

The report found that a substantial number of participants had not had any formal teaching time on sickle cell or thalassemia and had not nursed anyone with sickle cell or thalassemia. The report goes on to recommend that Approved Education Institutions should incorporate sickle cell and thalassaemia into all components of training by working alongside professional bodies and charities. The report also provides other practical recommendations for how this could be achieved.

At the launch, the recommendations of the report were outlined by Dr. Lola Oni OBE, Chair of the Nurses Education Advisory Group and Service Director of Sickle Cell & Thalassaemia Centre Central Middlesex Hospital London. Michelle Ellis, Senior Lecturer of Child Health at City University London, also offered the view of the educational establishment.

The launch was attended by partners, clinicians, supporters, service users and MPs including: Rt Hon Pat McFadden MP, Eleanor Smith MP, Bambos Charalambous MP, Baroness Benjamin OBE, DL, and Baroness Thomas of Winchester.

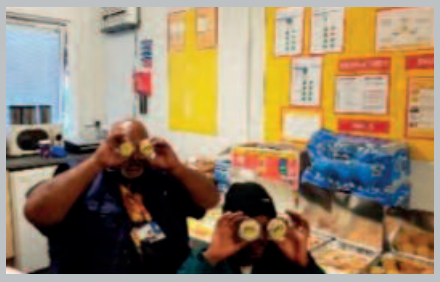
The report is a product of an advisory group set up five months prior to the launch, to formulate strategy, this was comprised of STANMAP (Sickle Cell & Thalassaemia Association of Nurses, Midwives and Allied Professionals) Sickle Cell Society, UK Thalassaemia Society, CNO BME Group and patient voices.

John James OBE of the Sickle Cell Society said: "This report confirms what the Society has known; that sickle cell and thalassaemia is not embedded in pre-registration training for nurses and midwives. The fact that the training is dependent on individual lecturers and schools is unacceptable. We hope that this report will lead to the inclusion of sickle cell and thalassaemia in the national curriculum and that we will see improved patient care and more trainee nurses in haemoglobinopthies."

Michelle Ellis, Senior Lecturer of Child Health at City University London

FUNDRAISING SPOTLIGHT

A big thank you to everyone involved with the Awedis Summer Fundraising Dinner. Thank you also to Tradition, Victor Romero Evens and Janet Kay for the entertainment during the evening.



Thank you to Imperial College Healthcare DHL for continuing to raise money for us.

A big thank you to Gerry Anderson who raised £307.20 with a collection tin at a music store in Harlesden.

A massive thank you to the Step Academy Trust who raised £398.15.

A massive thank you to Ilford Sport Club who raised £265 during Black History Month

Thank you to Westminster City Council who raised money for us by running three bake sales.

A massive thank you to the Medical Association of Nigerians Across Great Britain for raising £500 to support our work.

A big thank you to Queen's Park Community school for raising £600 for us.

Thank you to the Coopers Company & Coborn School for raising £590 to support us.

Thank you to all our Facebook Fundraisers for raising money with a special thank you to Kate Ogah who raised over £1000!

A massive thank you to James Crystal for climbing Mt Snowdon with a bag full of bricks on his back! [Image: James Crystal]

A giant thank you to Willis Tower Watson and Patrick Okolo for raising £1,471.56 plus for matching that donation to the grand total of £2,943.12!

A massive thank you to James Crystal for climbing Mt Snowdon with a bag full of bricks on his back!

Lucreta LaPierre

Friend of the Society, Sadly Passes Away

Lucreta LaPierre showing off her medal after running the British 10K in 2014

From left to right, back row then front: Martin Jordan, John James OBE, Stuart Wood, Lucreta La Pierre, Kalpna Sokhal at Cambridge United Football Club

Everyone at the Sickle Cell Society was deeply saddened to hear of the passing away of our long-time friend, volunteer, supporter and fundraiser, Lucreta LaPierre. She sadly passed away in hospital on the 29th November 2018.

Lucreta has contributed so much to the work of the Society, including raising considerable funds from her tireless fundraising activities over many years. She will be missed by staff and trustees, past and present. Our thoughts are with her family at this sad time.

You can read an interview with Lucreta from Spring 2006 online at: www.sicklecellsociety.org/lucretalapierre/

Children's Holiday 2018

On the 18th August the Sickle Cell Society took 30 children to the ACUK Pioneer Centre in Kidderminster for an action packed adventure holiday. Our annual children's holiday is always one the highlights of the year and this year was no exception. The children got to try new things and learn new skills during activities such fencing, archery and animal handling. The children also had the opportunity to face their fears with the high ropes, zip line and abseiling. Plus, there was plenty of time for fun and games such as team games, parachute games, table tennis, table football and more.

Education is also an important part of our children's holiday so time was set aside to help the kids learn more about managing their sickle cell and we were delighted to be joined by the ambulance service for an education session.

In the evenings we got to enjoy a disco and a campfire and the children got to show us their amazing talents at the talent show.

We are so grateful to our amazing volunteers; without who we wouldn't be able to run the holiday. A big thank you to: Dr Nellie, Nurse Hilda, Phillip, Holly, Chelsea, Rose, Joe, Caitlin, Precious, Betty, Chynia, Blessings, Murani, Jacky and Pansy

We are also thankful for all the wonderful people who have helped fundraise throughout the year to make the children's holiday possible.

"It's so nice to know our children are enjoying a break and are with kindred spirits. Good to know they are in safe hands. They all look very happy." Parent

Children's Holiday 2019

Like what you have seen of last year's children's holiday? Then don't miss out on the Children's Holiday 2019! You can register your child's interest at tinyurl.com/scs-holiday-19 The deadline is 1st April.

"I'm so grateful to the team for making this holiday so memorable, there really aren't enough words" Parent

"I am grateful to see my daughter go on a trip with others who share the same situation as she and I am grateful that I have got to know some parents as well" Parent

New Publications

"P is sooooo delighted and can't stop talking about the experience, from learning about priapism, listening to his body and understanding that nothing can stop him to the zip line experience. He has learnt coping strategies and built resilience. I am delighted and humbled" Parent

Newborn Screening for SCD in Europe

Sickle Cell Society CEO, John James OBE, is one of the authors of a new paper on new born screening across Europe. The paper, led by Stephan Lobitz, is the work of a group of European SCD specialists including one of our medical advisors, Dr Allison Streetly. *Newborn Screening for Sickle Cell Disease in Europe: recommendations from a Pan-European Consensus Conference* has been published in the British Journal of Haematology and shows the importance of cross-country collaboration.

The Role of Patient Organisations

John is also one of the authors for an article titled *Improving Screening Programmes for Sickle Cell Disorders and Other Haemoglobinopathies in Europe: The Role of Patient Organisations.* The article co-authored by Dr Elizabeth Dormandy and highlights the need for partnership and the important role that patient organisations can play in patient care.

Self Over Sickle Podcast

The Self Over Sickle programme (SOS) promotes improved physical, psychological, social and emotional wellbeing, primarily for young people aged 16-25. Focusing on areas of transition from moving away from home and dating to pursuing a career and raising a family, the sessions are entwined with games and creative activities to practically and positively impact all who attend.

The Self Over Sickle project is excited to launch a brand new podcast! Living with sickle cell? Know someone with sickle cell? Or just interested to find out more? Then join the conversation as we share the stories of Sickle Cell Warriors across the UK and the support available across the community. With the help and advocacy of healthcare specialists, and other local and national organisations we want to help you find your hopes, live your dreams and exceed your aspirations, because you may have Sickle Cell but Sickle Cell doesn't have to have you. Listen to the first episode below at anchor.fm/selfoversickle

The podcast is also available on most streaming platforms now including all your favourites: Spotify, Apple Podcasts, Google Podcasts, Stitcher and many more!

Introducing: South London Gives

The Sickle Cell Society are delighted to announce that NHS Blood and Transplant (NHSBT) have awarded us a tender to deliver an initial 1-year pilot project, 'South London Gives', which aims at increasing black African and black Caribbean blood donors.

The project will start running in four south London boroughs: Greenwich, Lambeth, Lewisham and Southwark, using a Community Organising model to reach into these populations. We aim to break down some of the myths, preconceptions and fears around blood donation and encourage people to sign up to become regular blood donors in their communities.

Community Organising is an approach that involves bringing people with joint interests together to take action and overcome areas of social injustice or inequality. The project will recruit and train Community Advocate volunteers who will connect with people and communities in their area to build a sustainable and resilient network of black blood donors who are committed to giving blood and positively impacting upon the lives of others. Each blood donation helps save or improve the lives of up to 3 people.

Although there is not a shortage of blood generally, NHSBT need to recruit a significant number of new blood donors from black African and black Caribbean communities due to an increase in demand for specific types of blood to treat sickle cell patients. Sickle cell patients needing regular blood transfusions benefit from more precisely matched blood, which is most likely to come from someone with the same ethnicity. More than 40,000 black African and black Caribbean donors are needed to meet this growing demand.

John James OBE, Sickle Cell Society Chief Executive said, 'We are thrilled to have the opportunity to make such a significant impact on the lives of people with sickle cell through this project. We already have an extensive network of committed community members in south London and look forward to involving many new Community Advocate volunteers through this work.'

For more information about volunteering or how your workplace, educational institution, faith group or community organisation can promote blood donation, please contact **Tracy Williams**, Project Manager, Community Organising /
tracy.williams@sicklecellsociety.org
07809 736099
Find out how you can donate blood at:
www.blood.co.uk

The Sickle Cell Society and South London Gives at an awareness event organised by NHSBT, in London City Hall with Mayor of London Sadiq Khan. (From left to right: blogger, Aliya Gladyng; Mayor of London, Sadiq Khan; SCS Treasurer/Vice Chair, Michele Salter; South London Gives Project Manager, Tracy Williams; and NHS Engagement Lead, Iyamide Thomas).

Congratulations to Lynette Adjei MBE

Huge congratulations to Lynette Adjei, long-time dedicated volunteer for the Sickle Cell Society, for being awarded an MBE for her services to Adoption and Fostering Recruitment during the New Year's Honours.

Helpline

The SCS Helpline Service provides confidential information, guidance, and emotional support to individuals and families affected by sickle cell living within the UK.

We understand that sickle cell disorders uniquely affect people, and can manifest into a range of further conditions. We also understand that a sickle cell disorder affects the wider social support network. That's why we support any individual affected by sickle cell, including family members, friends, employers, teachers and healthcare professionals. The topics we cover include:

Managing a sickle cell disorder
Social and welfare issues
Health and education provision
Housing and benefits entitlement
Employment support
Emotional support
Advocacy
Accessing services

Signposting to external agencies and support groups

You can contact our helpline service on **020 8963 7794** between: 10am and 5pm Monday – Friday

You can also use our confidential email service: **helpline@sicklecellsociety.org**. We will respond to all emails within 5 working days. We are also on social media: @SickleCellUK on Facebook, Twitter and Instagram.

Alternatively, please write to us: Helpline Services Team, **Sickle Cell Society, 54 Station Road, London NW10 4UA**.

Breaking Down Barriers

Breaking Down Barriers is a project focused on helping people living with sickle cell to overcome the various barriers they face. This could be anything from language barriers stopping them accessing informational resources to not being able to get the work or education that they want. Check out the highlights from everything that our Breaking Down Barriers officer has been up to:

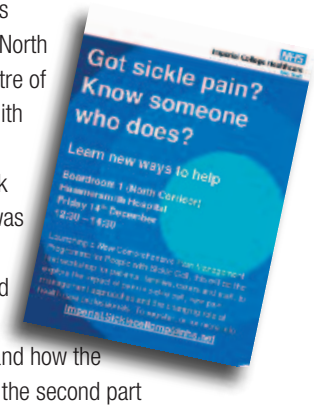
Black History Month

On the 25th October the Breaking Down Barriers project hosted an awareness stand at the Brent Council Black History Month event.

We were pleased to meet Cllr Arshad Mahmood, Mayor of Brent, at our stand and share more about the work we do.

New Comprehensive Pain Management Programme team

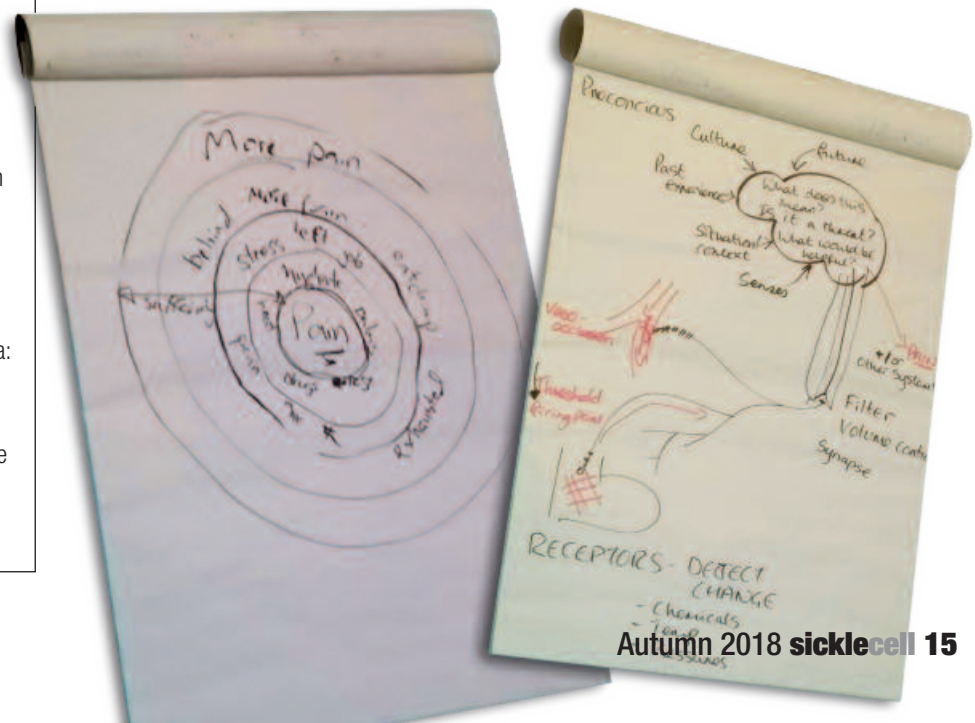
On Friday 14th December BDB was invited to Hammersmith Hospital's New Comprehensive Pain Management Programme. At the moment, the programme welcomes people with sickle cell in North West London, whose centre of care is either Hammersmith Hospital or Central Middlesex/Northwick Park Hospital. The workshop was divided in two sections. The first section explained the difference between acute and chronic pain, and how the body produces pain. And the second part addressed the difference between pain and suffering



If you have sickle pain or know someone who does and would like to attend the next workshop, please email **Imperial.Sicklecellpmp@nhs.net** to register or contact **linda.chic@sickecellsociety.org**

Resources

All the Breaking Down Barriers resources are now available to download for free online. The resources are in French and Portuguese and are translations of our "Did You Know" booklet, "Sickle Cell and Trait" flyer and the "Let's Talk About Sickle Cell" poster. You can download them here: **www.sicklecellsociety.org/breaking-down-barriers/**



SICKLE CELL SOCIETY

The Sickle Cell Society is Britain's only national charity for sickle cell disorders, an inherited haemoglobin disorder. The Sickle Cell Society was founded in 1979 by a group of patients, parents and health professionals who shared concerns about the lack of understanding of sickle cell disorders and the inadequacies of treatment. We aim to raise awareness of sickle cell disorders, push for improvements to treatment and provide advice, information and support to the sickle cell community. We produce information resources about sickle cell disorders, and hold at least three education seminars a year, as well as other awareness events. We provide a helpline service as well as an annual children's holiday to provide a respite break for children with sickle cell disorders and their families. We undertake lobbying work to draw attention to issues affecting the sickle cell community.

To become a member of the Sickle Cell Society please visit
www.sicklecellsociety.org/membership/
www.sicklecellsociety.org/donate
Charity number: 104 6631
Sickle Cell Society, 54 Station Road, London NW10 4UA
T: 02089617795

If you are no longer receiving letters or emails from the Society but would like to, please email info@sicklecellsociety.org to say that you wish to opt-in to Sickle Cell Society communications.
We will then update our database. You can contact us at any time to opt-out