

sicklecell



THE NEWSLETTER OF THE SICKLE CELL SOCIETY

SPRING 2022



In this issue:
The No One's Listening Report
New Sickle Cell Treatments
Give Blood Spread Love project
Plus so much more...

www.sicklecellsociety.org



Kye Gbangbola

John James OBE

Introduction

The last six months have been very significant for the sickle cell community and very busy for the Sickle Cell Society.

In October we heard the life changing news that for the first time in over 20 years, a new treatment for sickle cell, crizanlizumab, was going to be made available on the NHS. We have campaigned long and hard for new treatments to be made available, so it was very positive news, although long overdue. Four months later, at the start of February, we started to see the first sickle cell patients accessing crizanlizumab on a managed access agreement. We have more information on crizanlizumab and how you can access this new treatment later in this newsletter and we have also created a simple guide on our website:

www.sicklecellsociety.org/crizanlizumab/

Another major part of our work has been the 'No One's Listening' report. Following the inquiry into the tragic death of Evan Nathan Smith, and the many stories of failures in care we hear time and time again, we launched our own inquiry with the All-Party Parliamentary Group for Sickle Cell

and Thalassaemia.

In November, we published the findings of this inquiry in '*No One's Listening: an inquiry into the avoidable deaths and failures of care for sickle cell patients in secondary care*'. The report found "serious care failings" in acute services and evidence of attitudes underpinned by racism. The report also included a detailed list of recommendations for specific departments and organisations so we can accurately track progress and hold decision makers to account.

Thank you to everyone who contributed their experiences and stories. You can find out more about the report and the progress so far, including a Westminster Hall Debate and a meeting with the Secretary of State for Health and Social Care on page 12.

In the summer we enjoyed another virtual children's holiday. We have been running our annual children's holiday since the eighties, and the pandemic hasn't stopped us. Last year, to keep everyone safe, we brought the holiday online with an exciting range of activities. This children's holiday saw 52 families come together for a weekend of fun,

education and opportunity for children to meet other children with sickle cell and share experiences.

We are excited to welcome three new advisors to our team: Dr Rachel Kesse-Adu as a medical advisor and Giselle Padmore-Payne and Keisha Osmond-Joseph as nurse advisors. They join our team of medical, scientific and nurse experts, who play a vital role in ensuring that all of our work is accurate, up-to-date and relevant to the sickle cell community. They are all experts in their field, who volunteer their time and experience. Learn more about them on page 6.

Another piece of good news is around blood donation. Our 'Give Blood Spread Love England' project works extremely hard to raise awareness of the importance of blood donation and especially ethnically matched blood for people with sickle cell. We were excited to see new changes to blood donation rules which enable more black people to give blood. You can read about these changes later in this newsletter.

In November, we welcomed stakeholders, supporters, staff, and trustees to our office reopening. We have been based at our headquarters in Brent for over 40 years; during this time no major works or refurbishment had been undertaken. So it was with great

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pleasure that we were able to secure funding to have the ground floor redeveloped. The official opening was done by the former Mayor of Brent and dedicated supporter, Cllr Ernest Ezeajughi.

It is exciting to see progress being made in research. However, we know there is still lots of work to do to ensure there is a wider range of treatment options available for people living with sickle cell. The 'No One's Listening' report is a great achievement but is only the beginning if we are to see major changes being made. We are committed to ensuring these recommendations are followed and met with the Secretary of State for Health and Social Care, Sajid Javid MP, who was very supportive of recommendations to improve care for people living with sickle cell. We thank everyone who has supported our work and who continue to do so. It is with your support that we are able to continue our work and see real change happen.

John James OBE Chief Executive
Kye Gbangbola Chair of Trustees

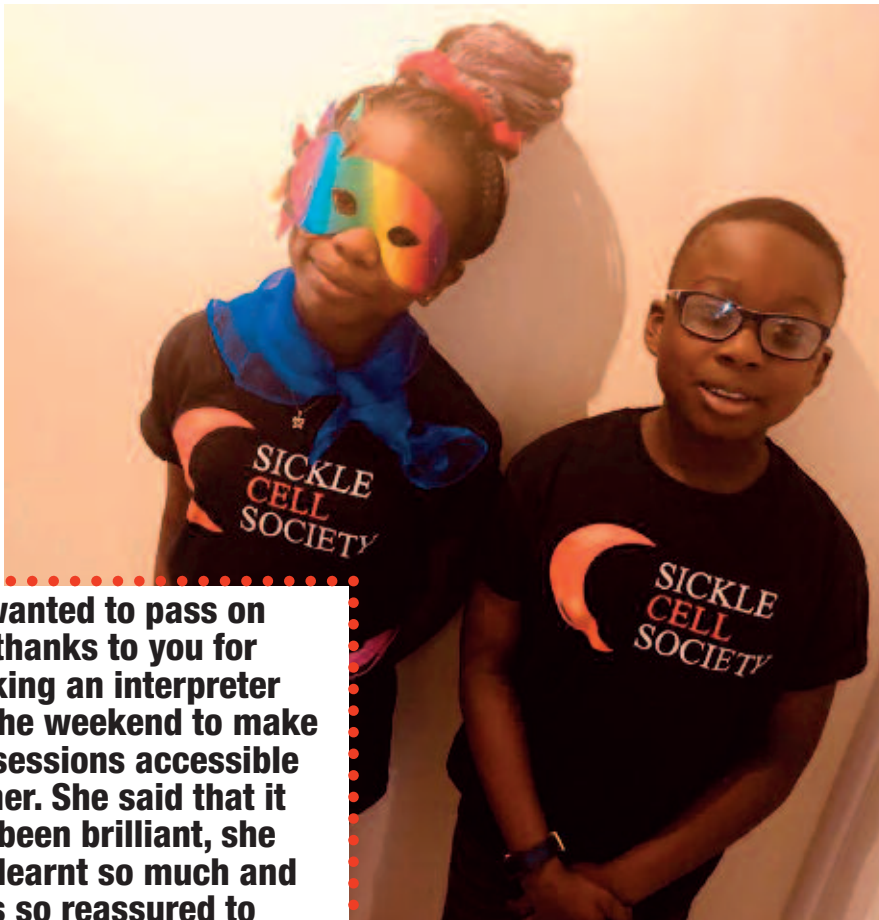


COVER
Lola E raising money for sickle cell by taking on the London Marathon

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Children's Holiday



“D wanted to pass on her thanks to you for booking an interpreter for the weekend to make the sessions accessible for her. She said that it has been brilliant, she has learnt so much and feels so reassured to know that other parents are in the same situation as her” – BSL Interpreter

The annual Children's Holiday is one of the highlights of our year. To continue keeping everyone safe, we held the holiday online again but that didn't stop us from coming together for a unique weekend of education, conversation and fun!

From Friday 13th August to Sunday 15th August we welcomed 52 families from across



the UK, for a virtual holiday delivered on Zoom with an accompanying activity box, and sessions jam-packed with fun activities.

We ran 3 different timetables, differentiated by age group - Bears for 4-8 year olds, Tigers for 9-12 year olds and Lions for 12-17 year olds as well as a programme for parents. The activities provided for each age group were designed especially for them and included:

- Cabin Chat and Games
- Sick Cell Information Sessions
- Animal Magic with Exotic Explorers
- Songs and Stories with Little Crowns Storyhouse
- Indoor Gardening
- Website Whizz Up
- SCS Bake Off
- Storytelling with Kwame
- Family Tai Chi
- Relaxation for Little Ones
- Girls and Boys Chats about Living With Sick Cell
- Carnival Dance
- Meditation
- We Are Resilient! We Are Confident!



“Thank you for this amazing weekend! What a feat pulling this off online so very successfully!!! Our family had an amazing time and it was valuable in so many ways that I don't know where to even begin! All I can say is ‘thank you!’” – a Parent

- Telling Your Story
- STOMP! Body Percussion
- Yoga
- Spoken Word
- Mindful Chocolate Tasting
- Meet A Star - Raise Your Aspirations
- Phone Photography

We also held a sibling chats session and four parent sessions to make sure the whole family was included. Every family also received an activity and equipment box to enable them to take part in some of the workshops, including some self-led screen free activities.

The children had a wonderful time. As they

2021

“I learnt so much in the parent sessions and feel like I have so many people I can fire questions at now if I need info or support” - a Parent



“I wasn't sure that any organisation could pull off a virtual holiday camp but it was excellent!” - a parent



“Thank you so much for giving us this opportunity. I had been worried about my son not having much to do this holiday because of our financial restraints. Having this opportunity made our weekend, it was a refreshing change to just watching films and playing games on the phone.” - Parent

told us, the holiday made them feel 'part of something' and 'not alone'. **The favourite part of the holiday, reported across the board, was meeting other children with sickle cell 'like them.'**

The holiday was led by Jessica Boatright and Taja Morgan (Children's Activities Leader) and the help of a wonderful team of 21 volunteers (including 8 doctors and nurses).

We also has 15 workshop practitioners leading some of the workshops and 1 British Sign Language interpreter who provided interpretation for one of the families.

Children's Holiday 2022

Following the success of last year's holiday, our 2022 Children's Holiday will also be held virtually. It will be running from Friday 5th to Sunday 7th August.

If you are interested in attending, would like to volunteer or just want to find out more, please get in touch by emailing: jessica.boatright@sicklecellsociety.org

Online Shopping

Buying online? Why not raise FREE donations to support our work with every online shop?

Online shopping has become increasingly important with more and more people avoiding the high-streets and getting what they need delivered.

With money being tight, you may not be thinking about donating to charity, but we want to show you a few options where you can raise donations, at no cost to you, with all your online shopping.

Find the option that is right for you below:

Amazon Smile

Amazon donates every time you shop online

Easy Fundraising

Turn your everyday online shopping into free donations

Give As You Live

Fundraise for us every time you shop online

Ebay for Charity

Raise money when you sell on ebay

Find out more about online shopping at our website:

www.sicklecellsociety.org/online-shopping/

Plus, check out our Charity Partnerships who are raising money through their great products.

If you run a business, big or small, then we would love for you to consider partnering with us, by donating a certain percentage of your profits.

If you are interested, then please email:

fundraising@sicklecellsociety.org



Welcome to our new advisers



Dr Rachel Kesse-Adu



Keisha Osmond-Joseph



Giselle Padmore-Payne

We are excited to welcome three new advisers to our team; new medical advisor and two new nurse advisers. Our medical, scientific and nurse advisers play a vital role in ensuring that all of our work is accurate, up-to-date and relevant to the sickle cell community. They are all experts in their field, who volunteer their time and experience.

Dr Rachel Kesse-Adu MEDICAL ADVISOR

BSc (Hons), MBBS, FRCP, FRCPath

Dr Rachel Kesse-Adu is a consultant haematologist who graduated in medicine from Imperial College School of Medicine in 2002, she completed her specialist training in haematology at Kings College Hospital in London in 2012.

She was appointed to a Consultant Haematologist position at Guy's and St Thomas Hospital where she continues to work. She has specialist interest in sickle cell disease and post graduate medical education. Her particular areas of interest in sickle cell are cardiorespiratory, chronic pain and urological complications. She runs joint specialist clinics in these areas. She is involved in clinical research in sickle cell disease and is the Training program director for haematology for SC London, and is heavily involved in teaching and training of haematology specialist trainees.

Keisha Osmond - Joseph NURSE ADVISOR

Keisha is a Haemoglobinopathy Lead Nurse at Barking, Havering & Redbridge NHT Trust. Born on the Caribbean island of Tobago, she travelled to the UK to pursue a career in Nursing – following in the footsteps of her grandmother. She leads a team of Haemoglobinopathy Clinical Nurse Specialists who provide high quality, comprehensive care for patients with Haemoglobin Disorders; from antenatal screening, in-patient, out-patient care through to community support. She has worked in several hospitals throughout East London and her career working with patients with SCD spans over 18 years covering acute, community, adults and paediatric

(including newborn screening). She is passionate about driving change and re-designing services to neutralise health inequalities, improve patient experience and health outcomes. Keisha is also an Academic Fellow and a guest Lecturer at City University.

Giselle Padmore-Payne NURSE ADVISOR

Giselle Padmore-Payne currently works at Croydon University Hospital as the Matron for Paediatric Outpatients, Paediatric Inpatient Services, Outpatients, Day Surgery and Quality Improvement. Prior to this Giselle worked as a Roald Dahl Transition and Lead Clinical Nurse Specialist for Adult Haemoglobinopathies with one-day a week in Paediatrics Haemoglobinopathies service at Kings College Hospital, overseeing a cohort of over 900 patients. Her academic background includes, prescribing for Nurses and Midwives (Level 7), MSc Social Research; BSc (Hons) Health and Social Care; Dip HE Nursing (Child Branch); Dip HE Sociology and certificate in Social Sciences, Cert in Mentorship.

She continues to develop her knowledge and skills through her involvement with a number of organisations and groups i.e. Roald Dahl Marvellous Children's charity ambassador; member of the South Thames Sickle and Thalassaemia Network (STSTN); member UK Forum for Haemoglobinopathies; Social Secretary of the Sickle and Thalassaemia Association of Nurses, Midwives, and Allied Healthcare Professionals (STANMAP). In addition, she is a Nightingale Scholar having recently completed the Florence Nightingale Leadership Course. Finally, winning the RCNi Nurse Award, 2020, in the Child Health Category has enabled Giselle to further raise the profile of the work being done around transition and sickle cell.

Bir**th**day **FUNDRAISERS**



Is your birthday coming up soon? Why not celebrate and raise money to support our work?

Facebook Fundraiser's are an easy way to raise money for sickle cell, with the help of your friends and family. Plus, it can all be done through your Facebook profile.

There are no fees for donations so all the money you raise, goes directly to supporting our work.

Join the hundreds of people who have already celebrated their birthday, and start raising money:

www.facebook.com/fund/SickleCellUK/

or go to the Sickle Cell Society

Facebook page on the Facebook app.

Plus, looking for tips and tricks to make the most of your fundraiser, or sample text you can use? Check out

our helpful Birthday Fundraiser page on our

website: www.sicklecellsociety.org/birthdayfundraisers/

Sickle Cell: Jamaica and Beyond

Looking to learn more about the history of sickle cell treatment across the world? Then check out 'Sickle Cell: Jamaica and Beyond'

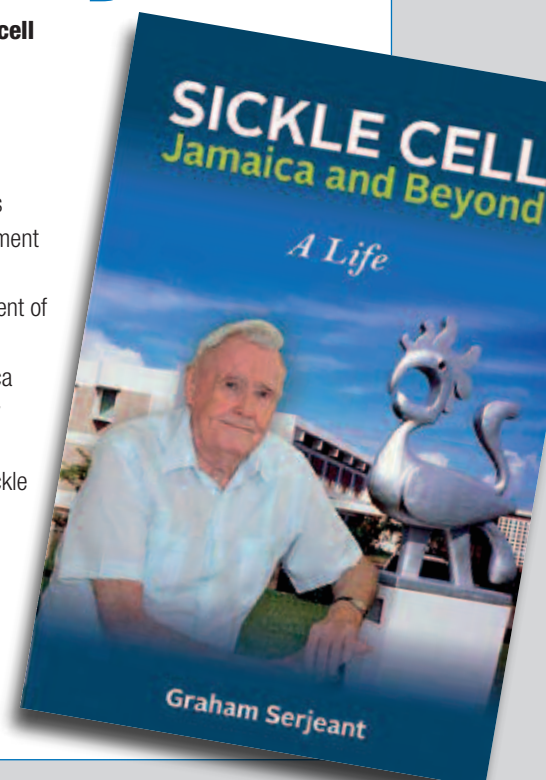
by Graham Serjeant.

In this book, Graham Serjeant tells the story of Jamaica's pioneering role in the diagnosis, treatment and management of sickle cell from 1967 until the present.

The book describes in considerable detail the development of services for patients with sickle cell, including its documentation, the setting up of clinics throughout Jamaica and the early establishment of newborn screening to study the disease from birth.

An enduring monument of this work is the dedicated Sickle Cell Clinic at the University Hospital of the West Indies – a purpose-built facility of the Sickle Cell Trust (Jamaica). Serjeant's account also details the contribution of the Jamaican experiences to services offered in Brazil, East Africa, India and Saudi Arabia.

If you would like to buy a copy, please email Graham directly: grserjeant@gmail.com



Change to blood donation rules ena



Give Blood, Spread Love's recent blood donation awareness event with PwC

Our Give Blood, Spread Love project welcomed Sajid Javid's recent rule change on who can give blood. Previously, anyone with 'a partner who has, or you think may have been, sexually active in parts of the world where HIV/AIDS is very common' such as 'most countries in Africa' were asked to defer donating blood for 3 months. This question, which was part of the pre-donation safety check, has now been removed after a long campaign by equalities organisations and MPs, including the vice-chair of the All-Party Parliamentary Group for Sickle Cell and Thalassaemia, Florence Eshalomi. In reality, the 'deferral period' meant that many potential black African donors and others in long term relationships were permanently prevented from giving blood and plasma.

This change, as with another earlier amendment which enabled more gay and bisexual men to donate, will have no impact on the safety of the blood donation supply. It is based on current scientific evidence and the recommendations of the FAIR steering group, a collaboration of experts in the UK blood services and LGBT+ charities and led by NHS Blood and Transplant (NHSBT).

In Give Blood, Spread Love's work engaging black communities on the topic of blood donation we have frequently met people who have been unable to donate blood due to this rule, or who have viewed its existence as

evidence of wider discriminatory practices within the blood donation service. We know how important securing trust from black communities is when asking people to donate blood, and how desperately needed ethnically matched blood is to treat people with sickle cell. We are hopeful that this significant and overdue change will encourage more potential black-heritage donors to come forward, and that the 12,000 people previously prevented from giving blood will recognise this call to action and restart their blood donation journey with our support.

Tracy Williams, Manager – Give Blood, Spread Love

All black-heritage blood donors, including those previously excluded due to the above rule, can sign up to save a life at: bit.ly/scsgiveblood

Florence Eshalomi MP's reaction shortly after the announcement of the rule change.

The full version of this article was first published in Labourlist.

This week offered a pretty special moment for me. I was sad my mum was not here to witness our success, however. I often think about my mum. We sadly lost her in 2015 at the tender

age of 60. It was cruel that she was taken so young. She neither got to see me being elected to the London Assembly nor to Parliament, but I know she would be proud, this week especially.

On Monday, the new Health Secretary Sajid Javid parted company from his predecessor by listening to the Black women in parliament – and our friends at Terrence Higgins Trust, National AIDS Trust and One Voice Network – and changing the rules on blood donor eligibility. A ban that should have been removed in June 2021 when the much-publicised outdated rules on gay and bisexual men donating blood were finally modernised. A ban that was removed in Scotland and Wales, but not England. A ban that hugely impacted potential Black blood donors, unnecessarily turned Black people away and prevented more from coming forward in the first place.

Based on antiquated HIV science, the rule was a three-month deferral period for anyone with "a partner who has, or you think may have been, sexually active in parts of the world where HIV/AIDS is common" and references "most countries in Africa". Existing robust screening rules means its deletion will have no impact on the security of the nation's blood supply. As Javid told the Evening Standard, deleting this question "will not compromise safety". It will reduce HIV-related stigma and is a win for many more besides.

In fact, the biggest beneficiaries will be sickle cell patients. People like my late mum. People who are Black African, Black Caribbean and of Black mixed ethnicity are more likely to have rarer blood groups and sub groups, including 'Ro', that many Black sickle cell patients need. 'Need' being the operative word.

As my mum's principal carer, I remember time and again how she would have to go for blood transfusions. They were part of her monthly cycle. We would dread the winter months, as the cold weather would exacerbate her sickle condition and mean more frequent treatment. That blood was literally her life support. Often, I would hear nurses talking about the need to put out an "urgent call" for more donations. In fact, I received a text of this nature from NHS Blood and Transplant a week ago last Wednesday. It was a telling reminder about the change we were fighting for.

Enable more black people to give blood

I remember being with my mum and being thankful to those who had donated, pint after pint. I remember hearing about this antiquated rule for the first time and thinking it just didn't make sense – both the question and the science behind it. I vowed to do something about it.

Since my election, it has been an honour to partner with Terrence Higgins Trust, National AIDS Trust and One Voice Network on this campaign. I was so proud of my colleague Taiwo Owatemi – a pharmacist by trade – who took up the same cause and worked with me and others to make the Health Secretary listen. Finally, it worked.

I hope this change is one less barrier to Black donors coming forward. That more ethnically diverse blood can flow into the NHS and patients like my mum. That there will be fewer Black girls fearing the winter and whether there will be enough blood for their mum each Christmas.

My mum will never benefit, but many like her will. Instead, I dedicate this victory to her, the wonderful Maria Da-Silva.

Florence Eshalomi is the Labour and Co-operative MP for Vauxhall, vice-chair of the APPG on HIV/AIDS and vice-chair of the APPG on Sickle Cell and Thalassaemia.

“The removal of this unnecessary and discriminatory question has been long overdue and will enable more people, particularly those of Black African heritage to safely donate much-needed blood products in England. During the bulk of 2021, we pressed UK government ministers - alongside our partners at One Voice Network and National AIDS Trust - to be guided by the latest science, not outdated evidence, which was used to justify this barrier to more donors from Black communities.

“We have been delighted to work with the Sickle Cell Society to press for this rule change to be reflected in NHS Blood and Transplant communications, such as its website, and the need for national awareness campaigns. Similar to what happened when changes were made relating to gay and bisexual men in

June 2021, we need to be shouting from the rooftops about this new rule change.

“Campaigns, just like the Society's *Give Blood Spread Love* initiative, are vital to empower more people from Black communities to step forward and donate.

“The removal of this question must now be a

catalyst for wider work to happen to address wider health inequalities faced by Black people in the UK.”

Glenda Bonde, Director of Equity, Diversity and Inclusion, Terrence Higgins Trust



Florence Eshalomi MP

Statement on Dr Mischa Brozovic



Standards Launch, Houses of Parliament 2018



Central Middlesex Hospital 1977

The Sickle Cell Society were deeply saddened to hear of the passing away of Dr Mischa Brozovic in December 2021.

Dr Brozovic was a pioneer for sickle cell in the UK, working as a Consultant Haematologist at Central Middlesex Hospital.

In 1979, along with Professor Dame Elizabeth Anionwu, Dr Brozovic set up the first UK nurse-led sickle cell and thalassaemia information, screening and counselling centre in Brent, North West London.

We are so thankful for all her contributions to sickle cell and our thoughts are with her friends and family during this difficult time.

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

We want to support you as best as possible, that is why we have opened up our helpline to 5 days a week from 10am to 5pm. Before calling, please see the correct number to call for each day of the week:

Monday, Tuesday and Wednesday

(10am-5pm) – 0780 973 6089

Thursday and Friday (10am-5pm) – 0208 963 7794

More details and any changes can be found on our website:

www.sicklecellsociety.org/helpline/

If you cannot get through to a member of staff, please don't leave a message but instead, call back later on.

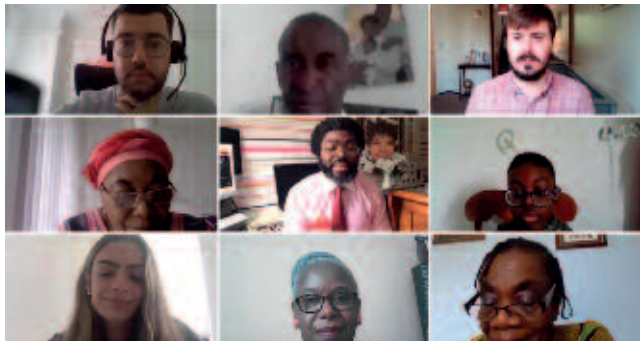
You can also use our confidential email service:

helpline@sicklecellsociety.org

Annual General Meeting 2021

On Saturday 11th September 2021, we joined with our members and stakeholders for our 42nd Annual General Meeting (AGM).

This was our 2nd virtual AGM and although we have missed seeing everyone in person, we wanted to keep everyone safe and it was great to see so many people attend, who normally wouldn't be



able to travel to London.

The AGM saw presentations by the Chair of Trustees, Kye Gbangbola, sharing the exciting work the Society has been up to over the past year. Society President, Michael Parker FCCA, CBE, then gave a full finance report detailing our income and expenditure.

This was followed by an interesting and informative Q&A session from our members about the finances and work of the Society.

After the AGM, we enjoyed the Emmanuel Amuta Poetry Award. Our NHS Engagement Lead, Iyamide Thomas, introduced the awards and we heard from this year's winner.

Thank you to everyone who attended, asked questions and entered the poetry competition. And of course, a massive thank you to everyone who continues to support our work!

You can watch the full AGM on our YouTube Channel: www.youtube.com/c/SickleCellSocietyUK/

Emmanuel Amuta Poetry Award

The Sickle Cell Society's Emmanuel Amuta Poetry Award is for creative young people aged 10-15 years who are living with sickle cell. The award has been created in memory of Emmanuel Amuta who suffered from sickle cell and sadly passed away on 19th September 2017, aged 14 years. Emmanuel was a confident, caring and gifted young man most cherished by the Sickle Cell Society. He was good at poetry and rap and really endeared himself to participants at the Society's AGM in July 2016 when he narrated his poem 'A Beautiful Cell'. This award will be his fitting legacy.

This year's winners were announced at our 42nd Annual General Meeting and we have included their brilliant poems below for you to enjoy.

You can read all of the entries at our website:

www.sicklecellsociety.org/resource/emmanuel-amuta-poetry-award-2021-winners/

Keep an eye out on our website and on social media for how to enter next year (usually around July/August).

1st Place:

'Sickle Cell and Me!' by Victoria O

Sickle Cell and Me,
At war in sea,
The sea of blood you see,
You can help win the battle with me.

Sickle Cell and you,
With pain on its side too,
Struggling to keep calm through,
But there are allies that want to help you.

Sickle cell and us,
Fighting with people we can trust,
The pain is causing a fuss,
But we can get through this, all of us.

Sickle cell and me,
We had a war at sea,
We made it through the crisis you see,
Thanks for fighting the battle with me!!!

2nd Place

'A Part Of Me' by Victor Ohaji (aged 13)

Although you're a part of me
You're the thing that causes me pain
You're the thing that causes a crisis
When I go out in the rain

My pain, my sorrow
My grief, my despair
Sometimes I blame my luck
And say it's not fair

Despite all these things
You're part of my identity
Despite all these things
You're a part of me

Engraved in my life
From the moment I existed

From that day on
The cold I resisted

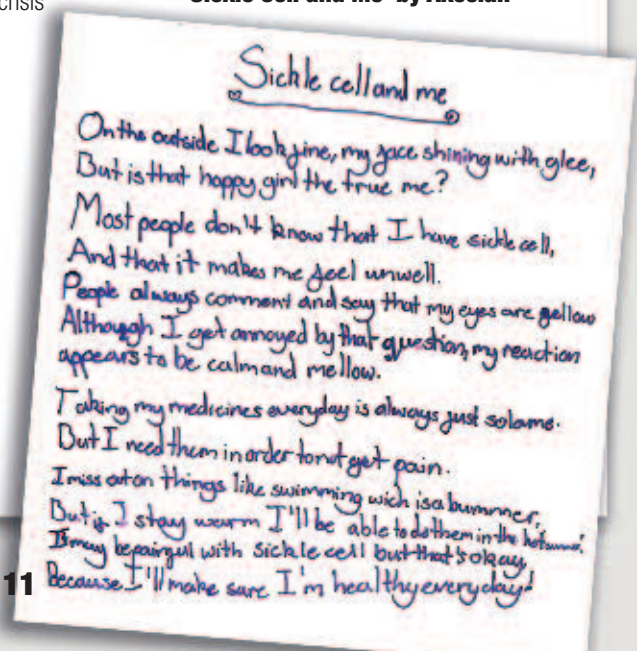
Blood cells,
The things that give us life
The things that go through our veins
Are the things that give me strife

When my friends go out longer than I do
I sometimes feel left out
And when my legs cramp up from running
I feel like I want to shout

But it won't stop me
From being what I want to be
For this is our journey
Sickle Cell and Me

3rd Place

'Sickle Cell and Me' by Akeelah





John James OBE

Pat McFadden MP

NO ONE'S LISTENING

MPs call for urgent changes to sickle cell care after inquiry finds "serious failings"

Report published following inquiry into avoidable deaths and failures of care for sickle cell patients.

An All-Party Parliamentary Group (APPG) inquiry report published on the 15th November 2021 highlights shocking failures as cross-party MPs call for major changes into care for sickle cell patients.

The groundbreaking inquiry, led by Rt Hon Pat McFadden MP, Chair of the APPG on Sickle Cell and Thalassaemia, has found "serious care failings" in acute services and evidence of attitudes underpinned by racism.

The full report can be downloaded at our website: www.sicklecellsociety.org/no-ones-listening/

The 'No One's Listening' report, which is based on the inquiry's findings, is jointly published by the APPG on Sickle Cell and Thalassaemia and the Sickle Cell Society, a national charity that supports and represents people affected by sickle cell disorders.

Key findings from the inquiry include:

- evidence of sub-standard care for sickle cell patients admitted to general wards or attending Accident & Emergency (A&E) departments (including a widespread lack of adherence to national care standards)
- low awareness of sickle cell among healthcare professionals and clear examples of inadequate training and insufficient investment in sickle cell care
- frequent reports of negative attitudes towards sickle cell patients and a weight of the evidence suggests that such attitudes

are often underpinned by racism

The inquiry also found that these concerns have led to a fear and avoidance of hospitals for many people living with sickle cell.

While the inquiry did find that specialist haemoglobinopathy services are generally felt to be of a good standard, the report shows that this is far from the case on general wards or A&E departments. Care failings have led to patient deaths and 'near misses' are not uncommon. **The inquiry heard that awareness of sickle cell among healthcare professionals is low, with sickle cell patients regularly having to educate healthcare professionals about the basics of their condition at times of significant pain and distress and that there is routine failure to comply with national care**



standards around pain relief when patients attend A&E.

Among the most notable of cases reviewed by the APPG was the tragic death of sickle cell patient Evan Nathan Smith in North Middlesex University Hospital in April 2019, which received renewed focus following the publication of the coroner's inquest in April 2021. The inquest found that Evan's death would not have happened were it not for failures in the care he received. The report highlights that high-profile cases of failings like these are sadly not isolated incidents and sickle cell patients all too often receive sub-standard care.

Worrying evidence of deep racial inequality in the healthcare system was found as part of the inquiry process. **Sickle cell is a condition that predominantly affects people with African or Caribbean heritage and patients often reported being treated with disrespect, not being believed or listened to, and not being treated as a priority by healthcare professionals even during cases where urgent medical care was needed. Some patients shared examples of particularly overt racism.** One patient said he has "had to deal with doctors and nurses openly being



Westminster Hall Debate



Rt Hon Sajid Javid MP

racist towards me and others ... I've been called the 'n' word to my face and much worse".

The report includes a number of recommendations and the APPG is calling on the Secretary of State for Health and Social Care, NHS England and NHS Improvement to prioritise taking urgent action.

Rt Hon Pat McFadden, Labour MP for Wolverhampton South East and Chair of the APPG for Sickle Cell and Thalassaemia, said:

"This is the most comprehensive report on sickle cell care that our All-Party Group has ever published. It has shown us that whilst people living with sickle cell generally had high levels of confidence in specialist haematology departments, there was a big gulf between this and the experience of A&E departments and generalist wards.

One of the key findings in the report was the lack of communication between these two areas when treating people with sickle cell, this, along with tragic and avoidable deaths, has caused a serious and damaging impact on the levels of trust in the health system among sickle cell patients.

In preparing this report we took extensive oral and written evidence from sickle cell patients, clinicians and others. The report calls for a comprehensive transformation in the care of people living with sickle cell. It also reflects the frustration that many of these arguments have been made for a long time without a proper response.

I hope this report is taken seriously by the Department of Health and Social Care and by the NHS. This time, we want people to listen because the inequalities in health care

highlighted in our report and the inconsistencies in treatment for people living with sickle cell have been going on for far too long."

John James OBE, CEO of the Sickle Cell Society, added:

"The APPG inquiry's findings are appalling but will sadly not come as a surprise to many people who have found themselves in need of urgent medical help for the symptoms of sickle cell.

I'd personally like to thank everyone who has given evidence and shared their experiences as part of this inquiry and particularly acknowledge the extraordinary bravery of the parents of Evan Nathan Smith who continue to fight so hard to prevent other families suffering from the loss of a loved one in such tragic and avoidable circumstances.

This report is an urgent call to action and should be a turning point that addresses these serious failures of care and secures long overdue improvements."

The inquiry is the first of its kind as it featured oral evidence sessions with testimony from expert witnesses including sickle cell patients, patients' carers and family members, clinicians and representatives from relevant healthcare bodies and over 100 submissions of written evidence from key stakeholders.

Westminster Hall Debate

On Wednesday 8th December 2021, the Rt Hon Pat McFadden MP, Chair of the All-Party Parliamentary Group for Sickle Cell and Thalassaemia (SCTAPPG), secured a Westminster Hall Debate to discuss the Treatment of Sickle Cell following this inquiry report.

The debate saw MPs discuss the findings and recommendations of the inquiry report, personal testimony from MPs with experience of family members and constituents with sickle cell, and a discussion of plans to make improvements.

You can watch the full debate at our website: <https://www.sicklecellsociety.org/westminster-hall-debate/>

Meeting with the Secretary of State for Health and Social Care

On Wednesday 2nd February 2022, SCTAPPG chair, Rt Hon Pat McFadden MP, Sickle Cell Society Chief Executive, John James OBE, and Parliamentary Officer, Seyi Afolabi, met with the Secretary of State for Health and Social Care, Rt Hon Sajid Javid MP to discuss the findings and recommendations of the 'No One's Listening' report.

It was a positive meeting and Sajid said he was very much listening. We are looking forward to seeing his plan to respond and will keep you updated with any developments.

Support this Report

We are so grateful to everyone who contributed to this report. We would love for you to support this report going forward to help ensure that we can see real change. See below a few ways you can help:

Write to your MP

We want to get as many MPs on board as possible, to enable the report and its recommendations to have the greatest impact. Please write to your MP to encourage them to support this report. You can do so by post or by email and we have created a template which you can use. Just download the template at our website, add your details and send the letter to your MP.

<https://www.sicklecellsociety.org/resource/write-to-your-mp/>

And find your MP by putting your postcode in here: www.theyworkforyou.com

Share this report

We want to make sure this report gets as much attention as possible. Please consider sharing this with your friends and family, with any support groups you are part of and on social media. Make sure to use the hashtag #NoOnesListening and tag us in @SickleCellUK

Thank you for your support!

First Sickle Cell Treatment in Over 20 Years



For the first time in over 20 years, a new treatment for sickle cell has been made available on the NHS.

On the 5th October, it was announced that eligible sickle cell patients in England and Wales will have routine access to a new sickle cell treatment, the first in over two decades.

Adakveo (crizanlizumab) will be made available on the NHS under a Managed Access Agreement (MAA), following the National Institute for Health and Care Excellence's (NICE) recommendation of crizanlizumab as an option for preventing recurrent sickle cell crises.

Sickle cell crises are one of the main symptoms of sickle cell. The pain occurs when the cells change shape after oxygen has been released. The red blood cells then stick together, causing blockages in the small blood vessels.

The new sickle cell treatment has now become available from the 1st February 2022.

To find out more about this new treatment and to see if you are eligible, please speak to your health care professional. You can also find a simple guide about crizanlizumab, the Managed Access Agreement and the eligibility criteria at our website:

www.sicklecellsociety.org/crizanlizumab/



“Sickle cell crises are extremely painful and disruptive to daily life, so it is very positive that a new treatment which can help reduce the number of crises for people living with sickle cell is being made available and funded by the NHS.” Sickle Cell Society, Chief Executive, John James OBE, explains.

“This new treatment is long overdue, being the first licensed treatment for sickle cell in the UK in nearly thirty years, which illustrates how underserved sickle cell has been over the decades.”

“We hope that this will be the first of many new treatments made accessible to improve the lives of those living with sickle cell, as well as enable sickle cell patients to have a wider choice of treatments.”

Other treatments

Other sickle cell treatments are beginning to become available to patients in the UK.

Voloxetor (formally GBT440) is a new sickling prevention medicine. The treatment is being made available via an early access program. If you want to know more or check your eligibility, please speak with your



healthcare professional.

We have been campaigning for a number of years to make more options available to people living with sickle cell. Through clinical trials a wider choice of safe and effective treatment for sickle cell will become available in the future but they need participants to make this happen.

A clinical trial is research which looks at how effective and safe a treatment or medicine is. One of the main reasons you may want to take part in a clinical trial is to help further research and to be part of the process which leads to new medicine and treatment for sickle cell.

You can find a list of UK based clinical trials at our website:

www.sicklecellsociety.org/clinical-trials/

Sickle Cell Society Exhibition 'Highly Commended'

We are so excited to have been 'Highly Commended' as part of the British Society for the History of Science Ayrton Prize 2021 for digital or online engagement!

Congratulations to Alinta Sara, Grace Redhead and site developer Juanita Rosenior and all the amazing people who contributed their stories to 'Our Journey, Our Story: History and Memory of Sickle Cell Anaemia in Britain, 1950-2020'.

The full exhibition is available digitally at our website:

www.sicklecellsociety.org/our-journey/



SIR TREVOR PHILLIPS

We want to wish our patron Sir Trevor Phillips a massive congratulations for being awarded a well deserved knighthood in the Queen's 2022 New Year's Honours





Iyamide Thomas, NHS Engagement Lead, Sickle Cell Society

UPDATE ON SCREENING 'ENGAGEMENT PROJECT'

health and other professionals working in the screening pathway. In my last update I stated that SCS and UKTS filmed interviews. The Societies have now viewed and endorsed the edits from this filming which will soon form part of the newly revised E-Learning resource.

These interviews discuss how the Societies work with the Screening Programme in areas including outreach, consultations with service users and advisory committees to help the Programme with its service delivery. We also hope that the extended versions of the interviews can be featured as separate videos called 'Society Stories', so watch this space!

provisionally planned a discussion with men for February. Let us hope that in our next newsletter I'll be able to report that this has taken place!

Standards'

Hard copies of the 'Parents Handbook' and 'Paediatric Standards' are now at the Sickle Cell Society, but as we are still working from home and doing very little outreach, these books are not yet available. However, they have now been distributed nationally to the various hospitals, sickle cell & thalassaemia centres and other relevant health professionals via the ten Haemoglobinopathy Coordinating Centres.

You can also access online from:

<https://www.sicklecellsociety.org/resource/parentsguide/>

<https://www.sicklecellsociety.org/resource/paediatricstandardsresource/>

If there was one 'good' thing about the pandemic it's how we have all been using innovative ways to communicate such as Zoom, Microsoft Teams and social media, enabling us to adapt our outreach and conveniently reach nationwide and global audiences! In October, I participated in an online conference by King's College Hospital ('Elements and Advances in Sickle Cell Care') which included topics such as Antenatal Haemoglobinopathy screening, Pre-implantation Genetic Diagnosis (PGD), Non-Invasive prenatal diagnosis for sickle cell and in-utero therapy for sickle cell. In November

First, A Recap!

The NHS Sickle Cell and Thalassaemia Screening Programme commissioned this 'Engagement Project' to work in collaboration with the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) to help ensure their service provision is underpinned by service user needs. The two Societies can work flexibly with communities affected by sickle cell and thalassaemia in a culturally sensitive way, gaining trust and useful insights that help inform the Screening Programme's policy and practice, whilst also helping to address any existing inequalities. We are currently in 'Year 4' of the project.

Project Update since our Autumn 2021 Newsletter

The Societies have been helping the Screening Programme revise its E-Learning resource for

Men Wanted!

We continue to conduct our online focus group discussions to gain valuable feedback on how information on sickle cell, screening and newborn results should be communicated, so the Screening Programme can make any relevant improvements. In December, I conducted a very useful discussion with five women who had not yet had children but who either had sickle cell trait or the full condition. It was interesting that most felt that trait status should be communicated in early childhood. In my Autumn 2021 update I reported on the focus group with 10 mothers. Yes, so far we've only been able to recruit women to the focus groups! That said, UKTS have managed to do one-to-one discussions with two fathers. So, I designed an advert specifically for the men and a few have indeed responded. As I type I have

Invisible Warrior Workshop: Sickle Cell and Dating

What does sickle cell mean for finding a partner?
How to discuss your genetics and talk about testing?
What are the moral, ethical and cultural dilemmas?

Join our exciting workshop to discuss these and other questions with a psychologist, patients, family and friends, and the doctors of the future.

13th December | **7.30pm-9.00pm GMT** | **Online workshop**

Patients, family, friends and medical students are invited to sign up by emailing: invisiblewarrior.scd@imperial.ac.uk

- Explore the impact of SCD on patients, friends, and family.
- Meet and chat with others in similar positions.
- Inspire and inform the next generation of doctors.

Sickle Cell and Dating Workshop InvisibleWarriorSCD

Sickle Cell Workshop: Screening

Antenatal and newborn screening are important to identify sickle cell disease.

Who, how and where can you request screening?
What are the emotional effects of this process?

Join our exciting workshop with Dr. Lola Oni who will discuss screening with a psychologist, patients, family and friends, and the doctors of the future.

1st November | **7pm-8.30pm GMT** | **Online workshop**

Patients, family, friends, and medical students are invited to sign up by emailing: invisiblewarrior.scd@imperial.ac.uk

With Special Guest Dr Lola Oni OBE FRCS Specialist Nurse Consultant

- Explore the impact of SCD on patients, friends, and family.
- Meet and chat with others in similar positions.
- Inspire and inform the next generation of doctors.

Screening Workshop (InvisibleWarriorSCD)

MEN with sickle cell or trait WANTED!
If you have a child under three years or no children at all

Take part in an online focus group to tell us:

- What you know about sickle cell
- What you know about screening for sickle cell
- How you think parents should receive their baby's newborn screening results
- What information you might need on sickle cell or screening

For your help you will get a thank-you gift voucher!

Please register your interest at:
www.sicklecellsociety.org

For more info go to:
www.sicklecellsociety.org/sickle-cell-awareness



A clip from the E-Learning video showing Iyamide doing outreach including raising awareness of screening

and December I participated in two relevant workshops: 'Screening' and 'Sickle Cell and Dating' run by the 'Invisible Warrior' sickle cell project at Imperial College. Several people with trait or the condition cited how stigma affected their dating experiences. This is why we must continue raising sickle cell awareness and dispelling some of the many myths and misinformation about the condition. We must also continue to do more outreach to young people who have not yet had children, giving them information on preconception testing and the various options available to them. By coincidence, after the dating workshop I also contributed to an interview in The Voice newspaper online on "Dating with Sickle Cell Remains a Taboo"! (<https://www.voice-online.co.uk/news/features-news/2021/12/17/dating-with-sickle-cell-remains-a-taboo/>).

I hope this update gives you an overview of what has happened with the 'Engagement Project' in the last few months. For more comprehensive information on the project please see the annual progress reports available on the Sickle Cell Society website: <https://www.sicklecellsociety.org/screening-programme/>

The Sickle Cell Society is the only national charity in the UK that supports and represents people affected by a sickle cell disorder to improve their overall quality of life. First set up as a registered charity in 1979, the Sickle Cell Society has been working alongside health care professionals, parents, and people living with sickle cell to raise awareness of the disorder. The Society's aim is to support those living with sickle cell, empowering them to achieve their full potential.

The Sickle Cell Society is a patient led organisation, our work is to benefit and improve the overall quality of life for patients as well as support those that are caring for them.

Becoming a member is a great way to support our work and get involved with everything we are doing.

Why become a member?

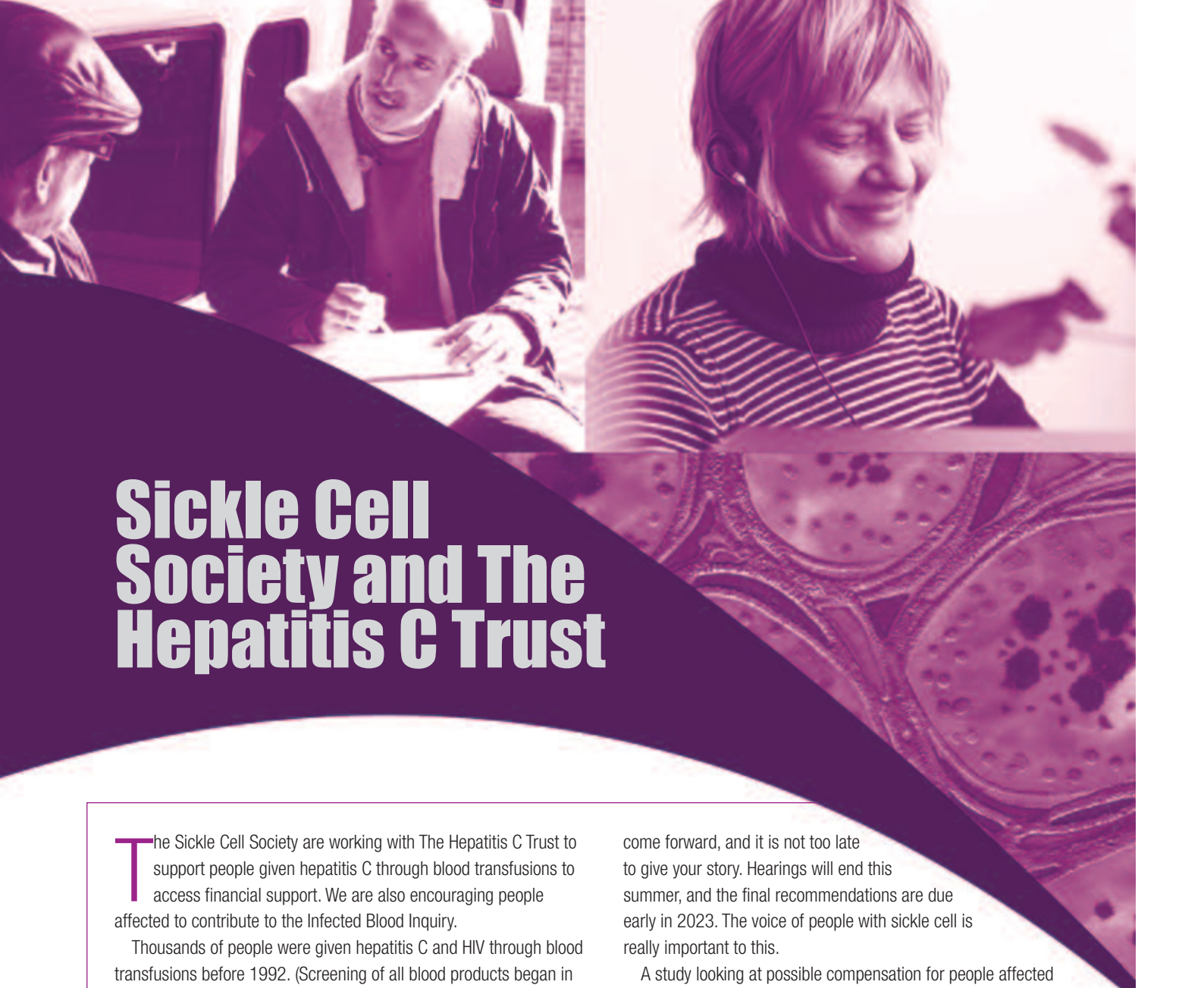
- Be the first to hear about the latest sickle cell research
- To share your experience and shape research and policy
- To be invited to our events and workshops
- To receive our monthly e-newsletter and twice yearly newsletter
- To have the right to vote at the annual general meeting which takes place in July each year



Become a Member

The Society's membership is open to all individuals who are aged 18 years and above, health professionals/organisations, corporate organisations and the general public. **Membership to the Sickle Cell Society is free!**

Please become a member today and support our ongoing work. Find out more here: www.sicklecellsociety.org/membership/



Sickle Cell Society and The Hepatitis C Trust

The Sickle Cell Society are working with The Hepatitis C Trust to support people given hepatitis C through blood transfusions to access financial support. We are also encouraging people affected to contribute to the Infected Blood Inquiry.

Thousands of people were given hepatitis C and HIV through blood transfusions before 1992. (Screening of all blood products began in 1991.) This includes people given blood and blood products during operations, following accidents, during childbirth and also for the treatment and management of conditions like sickle cell, thalassaemia and haemophilia.

The financial support schemes provide an initial lump sum of at least £50,000, and potential annual payments of between £18,000 – £28,000 for those who fit the criteria. Anyone given hepatitis C or HIV through blood or blood products is eligible to claim, or their surviving partners. Although the support schemes were set up many decades ago, many people are still unaware that they are eligible for this money. The Hepatitis C Trust can help people to apply for this.

The UK Infected Blood Inquiry continues to examine the events that led to this tragedy and how to avoid anything like this happening again. They are still asking for people affected and their families to

come forward, and it is not too late to give your story. Hearings will end this summer, and the final recommendations are due early in 2023. The voice of people with sickle cell is really important to this.

A study looking at possible compensation for people affected will also report to the UK Infected Blood Inquiry in March of this year. If compensation is recommended by the Inquiry, this report will set a framework for what any compensation system should look like.

The helpline team at the Hepatitis C Trust can help with contacting the Inquiry, and applications to the existing payment schemes, as well as answering any questions you may have in connection with hepatitis C.

You can contact them on their helpline 020 7089 6221, or by email helpline@hepctrust.org.uk, or via message on Facebook www.facebook.com/HepatitisCTrust

You may also contact the Sickle Cell Society's Helpline on 0780 973 6089 or by email helpline@sicklecellsociety.org who will be able to provide you with some initial information on the help available, prior to being referred to the Hepatitis C Trust for practical support, if you wish. All calls are confidential.

THE HEPATITIS  TRUST

On Monday 29th November, we re-opened our office after the phase-one of our refurbishment.

We have been based at our headquarters in Brent for over 40 years; during this time no major works or refurbishment had been undertaken.

In 2019, we secured the lease-hold of the Ground Floor to the adjoining building with the view to develop our existing premises and the neighbouring ground floor shop space into a comfortable, accessible and welcoming reception area and meeting space for the sickle cell community.

We are extremely grateful to four key funders who awarded the Society with grants to fund this first stage of our refurbishment. Brent Council were the impetus in terms of their initial grant, received via the Neighbourhood Community Infrastructure Levy (NCIL). This enabled us to leverage grants from the Garfield Weston, Clothworkers and Bernard Sunley Foundations to completely fund Phase 1. We

OFFICE OPENING

were able to begin the first phase of refurbishment: downstairs.

At the end of November, we were excited to be able to invite a handful of guests (keeping COVID safe) to celebrate the re-opening of the offices and to show off the refurbishment.

The event started by welcoming in the guests for light refreshments. Guests included the former Mayor of Brent and dedicated supporter, Cllr Ernest Ezeajughi and his wife, Sickle Cell Society staff and trustees, representatives from grant funders, the architects and project manager, community activists, and other stakeholders and supporters. We also welcomed guests virtually, with our new conference system, including SCS

patron, Professor Dame Elizabeth Anionwu.

Cllr Ernest Ezeajughi opened the official part of the event by welcoming everyone and speaking about the work of the Sickle Cell Society over the last 40 plus years. He then unveiled the plaque, to mark the official opening.

Chair of Trustees, Kye Gbangbola then gave a short speech followed by a few words from Dame Elizabeth Anionwu.

The event concluded with a few group photos in front of the plaque and in front of the building.

The downstairs refurbishment is just phase one of our plans to improve the building. We will also refurbish the 2nd and 3rd floors.

None of the general donations go towards this refurbishment, (and only goes to support our work to improve the lives of those living with sickle cell). But this means we need to do extra fundraising to ensure the refurbishment can go ahead.

If you would like to support us you can do so by email fundraising@sicklecellsociety.org



An Update on COVID-19

Since the pandemic started, we have worked with our medical advisors and other healthcare professionals to ensure the sickle cell community had clear, up-to-date and sickle cell specific information and guidance on COVID-19. The hub for this information has been on our website:

www.sicklecellsociety.org/coronavirus-and-scd/

We have also held four Live Q&A sessions, with panels of experts answering your questions. The panels included:

- Professor Adam Finn (Professor of Paediatrics and Member of the Joint Committee on Vaccination and Immunisation)
- Professor David Rees (Consultant Paediatric Haematologist and SCS Medical Adviser)
- Dr Mark Layton (Consultant haematologist and SCS Medical Adviser)
- John James OBE (Chief Executive of the Sickle Cell Society)
- Dr Kofi Anie (Consultant Psychologist and SCS Medical Adviser)
- June Okochi (Head Of Program Management at NHS West Essex CCG, and Lead Mentor of SCS Mentoring Programme)

The full recordings can be found at our website:

<https://www.sicklecellsociety.org/liveqanda/>

We also felt that vaccination was an important part of protecting the sickle cell community, so we worked with healthcare professionals to create an information video series.

The first video was an overview of the COVID-19 vaccine with Dr Anna Goodman, Consultant in Infectious Diseases and General Medicine at Guy's and St Thomas.

We then spoke with Dr Rachel Kesse-Adu who shared the data we have so far on COVID-19 and sickle cell, collected from sickle cell centres from around the country. In this video, Dr Abbie Wickham (clinical psychologist) also gave a presentation on how to make difficult decisions about your health. The video concluded with a Q&A session.

In the final video we spoke to sickle cell patients, Emma, Liz, Ayo and Ansellia about their experience, why they got the vaccine and if they had any side effects. We also heard questions from Anthony, a sickle cell patient who was yet to have the vaccine.

All these videos can be found at our YouTube channel:

www.youtube.com/c/SickleCellSocietyUK/

Current Guidance

The government is removing remaining domestic restrictions in England. They have provided steps you can take to reduce the risk of catching and spreading COVID-19. These include:

- Get vaccinated
- Let fresh air in if meeting indoors, or meet outside
- Consider wearing a face covering in crowded, enclosed spaces
- Get tested if you have COVID-19 symptoms, and stay at home if positive

Although the restrictions are being removed, we will continue to update our website with information and guidance specific to people living with sickle cell.

The National Haemoglobinopathy Panel (NHP) have provided data on haemoglobinopathies and COVID-19, how many people have got COVID-19, hospitalisation and outcomes. You can find this data at the NHP website: www.nationalhaempanel-nhs.net/



Leaving a Gift

Leave a gift in your will and transform the lives of those living with sickle cell.

15,000 people in the UK live with sickle cell; a genetic blood disorder causing anaemia and episodes of severe pain. Over time people with sickle cell can experience damage to organs such as the liver, kidney, lungs, heart and spleen.

For over 40 years, the Sickle Cell Society has been working alongside patients, families, and healthcare professionals to raise awareness, provide support and empower people living with sickle cell to achieve their full potential. The Society works both at ground level within the community and on a national level through campaigning for policy changes and supporting research.

By leaving a gift to the Sickle Cell Society you are joining that legacy and helping to improve the lives of future generations.

When you leave a gift in your will, we make a promise to continue supporting the sickle cell community. Your support enables us to reach more people, run more activities, and improve more lives.

After taking care of your family, why not leave a gift to support the Sickle Cell Society and help transform lives?

Find out more about leaving a gift in your will at:
www.sicklecellsociety.org/leaving-a-gift/
or by calling our Fundraising Officer on 020 8963 7793

Thank you, we greatly appreciate your support.

RUN A HALF MARATHON FOR SICKLE CELL

Are you passionate about running? Have you ever participated in a marathon or half-marathon? Do you like challenging yourself? Then this is the perfect opportunity for you!

The Sickle Cell Society has entry tickets to two half marathon events and we want to give them to you! If you want to raise money for sickle cell and take part in fun and exciting challenges, then please keep reading!

Hackney Half Marathon

Only 5 places available.
Taking place on Sunday 22nd May 2022
Deadline for application for slots is Thursday 31st March.

Royal Parks Half Marathon

Only 3 places available
Taking place on Sunday 9th October 2022
Deadline for application for slots is Sunday 31st July.

To apply or to get further information on either event, please email: fundraising@sicklecellsociety.org

FUNDRAISING SPOTLIGHT

A massive thank you to our London Marathon Runners, Robert Johnson £712, Ayodeji Akande £1812 and Wari Orumbie £342 for raising money for sickle cell.

A very special thank you to Jane Wells who run the London Marathon on our very own SCS ticket to raise an incredible £2,431!

A big thank you to the students at Christ the King Sixth Forms who raised £500 with a sports tournament

A big thank you to Joss Freeman for raising £165.95 by running the virtual London Marathon

A massive thank you to Kizzy Constantine for running the London Marathon and raising £1,088

A massive thank you to Charlotte Tweddle for raising £1166 by taking on the Jurassic Coast challenge.

A big thank you to Louise Akrofi for raising £500 with the Jurassic Coast Challenge

A big thank you to Keith Harris for raising £270 with a fundraising walk.

A massive thank you to Marian Shasanya for raising £1050 with a fundraising skydive.

A huge thank you to Stanley Marrast for raising £607 with his third Isle of Wight Challenge!

A big thank you to Accenture's Corporate Functions African Caribbean Network for raising £1630 with a mile a day challenge.

A massive thank you to the Ten Toes team, a group of ten young men from South East London who raised £4075.68 with a 10km challenge for us and The Ben Kinsella Trust.

A huge thank you to Wari Orumbie for running the London Marathon and raising £545.19.

A big thank you to Courtney Green for celebrating his birthday by raising £1269

A massive thank you to Winnie Greer for raising a tremendous £1,141 with another fantastic evening of big band jazz.

A big thank you to David Thomas who ran 100km and raised £600 for sickle cell in memory of David Skinner.

A big thank you to the Power Puff Girls Team, Rosalie Russell, Tierah Wilson and Sophia Antoniadis who raised £765 by taking part in Battle Cancer London in October.

A massive thank you to Michelle, Rachael & Joel who raised £1,020 by completing a marathon distance by walking, running and cycling

A big thank you to ClearBank who raised £1,255 as part of Black History Month.

A massive thank you to the employees of Metro Bank for raising £503 through their Black History Month Raffle.

A big thank you to Linda Green who raised £628 for sickle cell in loving memory of Albert Jones.

A big thank you to Claire Walton for raising £100 in memory of Spurgeon's dear twin Brother, Sister And Mother Smith.

A big thank you to Mount Zion Youth Society UK who raised £935 to honour the memory of their dear sister and friend Jennifer Phillips.

A huge thank you to Gregory Greenfield who has raised £513 with his bike ride to Asia.

A big thank you to John A Wilson for raising £580 with his Riding the Triangle - long distance motorcycle ride.

Thank you to North Highland BAME for raising £420 with their charity raffle.



A massive congratulations and thank you to Clara Amfo and Johannes Radebe for their amazing performance on The Hit List and for raising £8,454 to support our work!



Enfield County School for Girls



A huge thank you to Aminah Jelani for raising £542 with a 60 day chin-up challenge.



A massive thank you to Omobola Jibodu for raising £1055 to celebrate her birthday.



A massive thank you to Tim, Solomon, Dan, Melvyn and Paul for raising £2096 with a 145 mile, coast-to-coast cycle ride in memory of Candice Woodcock.



A big thank you to Darren, Joanna and Rachel for raising £2744 with the London to Brighton Cycle Ride in loving memory of their Uncle Peter.



Thank you to Business & Law students at Central Saint Michael's Sixth Form who have raised over £200 with a food stall in their reception area.

A massive thank you to everyone who raised money for us with a Facebook Fundraiser. We deeply appreciate your support. A special thank you to our top Facebook Fundraisers: Lynette Tunde Adjei, Betty Gondwer Driver, Victor Kenny Macarthy, Cassius Francis and Lydia Okoibhole.



A massive thank you to the Mayor of Waltham Forest, Councillor Elizabeth Baptiste, for raising money with a guided walk, led by Des Aherne. Thank you to everyone who came along!



A big thank you to Dr Francis Okoro and Nduoma Chilaka who raised £3,345 with their Ben Nevis climb.



A massive thank you to Jess Rosewell for raising £1047 by walking over 10km a day over a period of 6 months (totalling 2109.7k km)!



A huge thank you to Roxie George for raising £454 with the Isle of Wight challenge.



A huge thank you to our Vice Chair and Treasurer, Michele Salter and everyone at Nezwick Jive for raising £198.54 at their charity dance night



A big thank you to Chioma and Steven for their walking marathon/bridge to Brisbane race which raised £700 in memory of their Joseph Otigbah.



Massive thank you to Hakeem Osinaike and all the employees of Brent Council who abseiled down their own 13-storey high Lexington House Building on 12 November 2021 to raise an amazing £8,291!



A massive thank you to Veolia Southwark Integrated Waste Management Facility, and Lucian in particular, who raised £643.80 to support our work. The money donated was coins that have been thrown away by residents and then got stuck to the magnets on the machinery here. Lucian diligently collected these over the past year and a half and then donated them to us as we are very close to his heart.



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The Society's aim is to support those living with sickle cell, empowering them to achieve their full potential. 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 education and

awareness events. We provide a helpline service as well as an annual children's holiday and children's activities 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
Telephone: 02089617795
www.sicklecellsociety.org



www.sicklecellsociety.org/donate