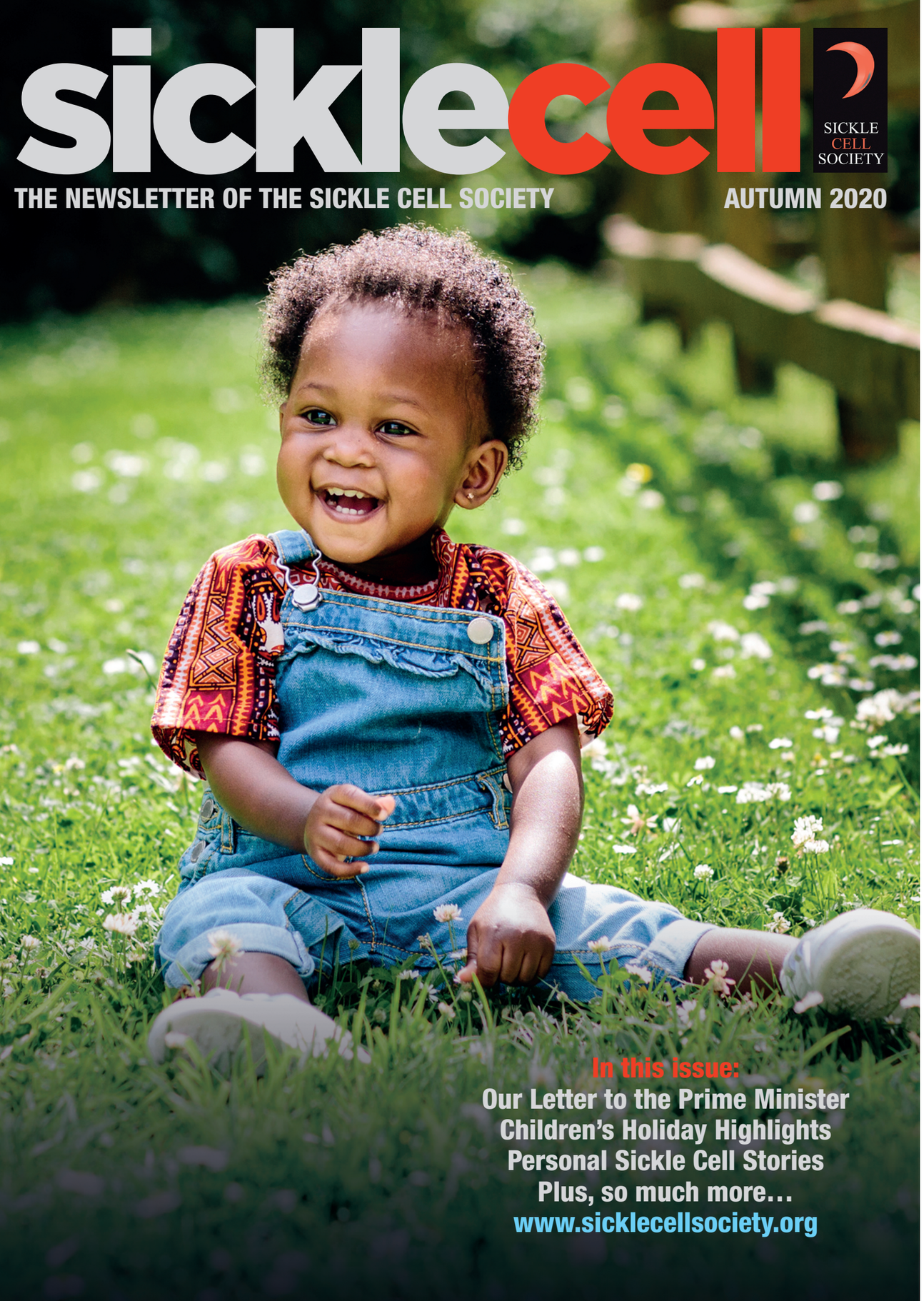
sicklecell

SICKLE CELL SOCIETY

THE NEWSLETTER OF THE SICKLE CELL SOCIETY

AUTUMN 2020



In this issue:

Our Letter to the Prime Minister
Children's Holiday Highlights
Personal Sickle Cell Stories
Plus, so much more…
www.sicklecellsociety.org

Contents

Sickle Cell Society Newsletter Autumn 2020

Cover
Suki - one of the youngest sickle cell patients to rely on donated blood

Editor Matthew Neal
Sickle Cell Society 54 Station Road London NW10 4UA
T. 020 8963 7798
E. matthew.neal@sicklecellsociety.org

Introduction

The last six months have been an unprecedented time for everyone. With the rise of COVID-19, life over the last six months has been very different, but no less busy for the Sickle Cell Society. With sickle cell falling into the clinically extremely vulnerable category, we felt that it was vitally important that our work and support continued, albeit with changes to ensure the safety of staff, volunteers and our service users.

We felt it important to make sure our members had up-to-date advice and guidance specific to sickle cell, and to create a space in which anyone could ask questions and get informed and expert answers. That's why we developed a specific page with our medical advisors to give guidance on sickle cell and covid. We were delighted to get positive feedback from across the world from patients and clinicians about the helpful information on our website.

Further to that, we ran three Live Q&As. Open to everyone across the UK (with people also logging on from across the globe), the Live Q&As provided a platform for our members to get answers and support on areas which the general guidance may not cover. The panels were made up of Society staff, our medical and scientific advisors and patients. The most recent of our Live Q&As also saw presentations on research and data around sickle cell and covid. You can read more about this later in this newsletter.

With the aim of continuing our services and support, we also held our first ever Virtual Children's Holiday. Our Children's Holiday has been an annual event since the 1980s and is one of our highlights of the year. This year was no different, with our team creating a fun, creative and educational weekend, only this year it was held online. You can read all about what the 30 children and young people got up to later in this newsletter. You can also read about our Children's Activities, recently restarted online with funding from Global's Make Some Noise.

Another first for this year was our first ever virtual AGM. Held a little later than usual (in September) our AGM was an opportunity for members to learn more about our work over the past year, ask questions about our annual accounts and look towards the future of the Society. It was great to see and hear from so many of our members who attended.

Discussing our finances was especially relevant this year. Across the charity sector the pandemic has made a significant impact on funding, and the Society is no exception to this. With the cancelation of most in-person meetings, sponsored activities and events, fundraising came almost to a standstill. We are so grateful to all our supporters and fundraisers who got creative with the fundraising and found new ways to support our work. That fundraising and donating has proved vital to enabling us to continue supporting people living with sickle cell. However, the challenge is far from over. We still need people to donate and fundraise for us. You can find out ways to get involved and support our work later in this newsletter.

We would like to take this opportunity to also welcome two new trustees to the team; Mr Shubby Osoba MBA and Nathan Hepburn. Our trustees play an important role in the governance of the Society and we look forward to working with Shubby and Nathan. You can learn more about them and why they have chosen to join the Society later on. We would also like to say a massive congratulations to our patron, Derrick Evans (Mr Motivator) on receiving an MBE in the Queen's Birthday Honours.

On the 19th June we celebrated World Sickle Cell Day. Being at home didn't stop the celebrations, as we ran and took part in a range of online events, looking at the history of sickle cell in the UK, sickle cell's discovery in West Africa and on the future of sickle cell across the globe. Our chair spoke at the GASCDO Global Conference with eminent speakers from across the world, discussing advocacy and public policy in respective countries. We also promoted awareness and education online as well as running a Wear Red for Sickle Cell campaign. It was great to see so many people getting involved and wearing red, including our patron, Eastenders actress, Ellen Thomas.

At the heart of our work is the sickle cell community. Although statistics play an important role in improving care and in supporting research, hearing the real stories of people living with sickle cell is also vital. We have a few 'patient perspectives' for you to read in this newsletter, including from our Project Engagement Officer, Layla, in a joint awareness campaign with NHS Blood and Transplant which featured on The One Show.

Our work promoting blood donation has also thrived with our new project. Give Blood, Spread Love is the new digital arm of our South London Gives project, sharing the same commitments and goals, but relocating them into the digital world. The project has started strong with a growing Instagram community and the recruitment of members to the Give Blood Squad. We are excited to see how this project grows and develops.

We have also seen developments in other areas of sickle cell care and research. You may remember that we previously were looking to get people involved in the Sickle Cell Service Review, a review of NHS England's planned changes to short and long stay hospital admissions for people with sickle cell. Thank you to all who got involved and shared your thoughts. As part of the proposed changes were the introduction of Haemoglobinopathies Coordinating Centres (HCCs). We detail the roles of the HCCs and where they are, later in the newsletter. Plus, we talk about a liquid formulation of hydroxycarbamide now available in Scotland, research we are doing into sickle cell and covid and an update on the finding of Sickle Cell World Assessment Survey. All this and more can be found in this edition of our newsletter.

In these difficult times we are committed to making sure that support for the sickle cell community continues to grow and that the profile of sickle cell increases on a local, national and global stage (make sure to read the article on our letter to the Prime Minister in this issue). Thank you for all your support and we hope you enjoy this edition of the newsletter.

John James OBE Chief Executive and
Kye Gbangbola Chair of Trustees

John James OBE *Kye Gbangbola*

South London Gives meets Give Blood, Spread Love

South London Gives, Sickle Cell Society's community blood donation project, is delighted to welcome Give Blood, Spread Love. Led by Olivia Anastasiou, our new Digital Marketing Officer for Blood Donation, Give Blood, Spread Love will work collaboratively with South London Gives and use new media to 'turn up the volume on blood donation' within and beyond the sickle cell community.

In its infancy, Give Blood, Spread Love is our exciting new digital arm of South London Gives, sharing the same commitment to increasing the number of black-heritage blood donors, but situating it into the digital world.

Through building a community of social media users, 'the Give Blood Squad', to represent and share vital messages about blood donation, this new project will target young and socially engaged audiences, as well as build partnerships with likeminded community organisations, university societies, sickle cell support groups and businesses of interest.

Speaking about this new project, Olivia said, *"I am really excited about Give Blood, Spread Love. It is an important opportunity for us to build upon the work South London Gives is doing and to contribute to increasing the numbers of black-heritage people regularly donating blood. People most severely affected by sickle cell frequently need ethnically matched blood as part of their treatment. Currently, there is nowhere near enough people of black heritage coming forward to meet this need. Working collaboratively with South London Gives, our aim is 'turn up the volume' of blood donation among our target communities and vastly increase the number of new black and mixed race blood donors."*

Sickle Cell Society's goals for this new strand of our blood donation work are ambitious. We aim to eradicate negative perceptions around giving blood and ultimately make giving blood a 'movement', one which challenges cultural and societal norms and that harnesses the power of peer to peer encouragement and support.

Give Blood, Spread Love's first campaign launched in September and asked people to not only 'Give Blood', through registering to become a blood donor through our simple registration process but to 'Spread Love', by sharing they have signed up to become a donor across their social media platforms. Contributors share either a screenshot of their submitted blood donation form, or a selfie of them giving blood, nominating three people to do the same, by tagging them in their post.

Give Blood, Spread Love is operating in London and Birmingham and will have a team of volunteers dedicated to raising awareness in these areas. Volunteers will invest more involvement than our 'Squad', by committing to more hours of support. Our volunteers will share online messaging, as well as develop relationships with both organisations and individuals, encouraging them to join and contribute to our cause.

For more information, to join the Give Blood Squad or to volunteer in London or Birmingham contact:
olivia.anastasiou @sicklecellsociety.org

FOLLOW US
Instagram
@sicklecelluk
@givebloodspreadlove
Twitter
@givebloodlove
#SouthLondonGives #GiveBloodSpreadLove
#GiveBloodSquad

Give Blood, Spread Love is funded by Terumo

South London Gives

Now in its second year, South London Gives (SLG) is continuing with its extensive programme of community engagement activities designed to break down the myths and fears that exist around blood donation in some black-heritage communities. SLG's aim is to raise awareness about the blood donation process with the ultimate goal of increasing the number of black-heritage people regularly donating blood.

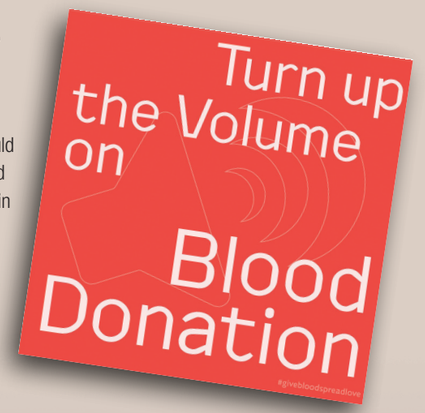
As with similar community engagement projects, the Covid 19 crisis severely affected South London Gives' work. Government restrictions on travel and a need to safeguard our staff and volunteers meant that we placed our face-to-face recruitment of new blood donors on hold for four months. However, after a challenging, but exciting period of restructuring, South London Gives relaunched its donor recruitment work in July. Now, instead of meeting us in person, we are asking our supporters to join us online for a range of sickle cell awareness raising and blood donor recruitment sessions designed to highlight the link between sickle cell and the need for more black heritage people to join the donation register.

Since restarting this work, South London Gives has collaborated with the Society's heritage project, *OUR JOURNEY, OUR STORY*, to present the history of blood donation campaigning. 'Sickle Cell Disorder and the Call for Black Blood Donors', featured sickle cell disorder advocates including our patron, Professor Dame Elizabeth Anionwu, and looked at the sometimes controversial discourse surrounding black blood donation over the past 40 years. In August, we held an interactive online discussion about the importance of blood donation for individuals with sickle cell, featuring SLG volunteer, Bola Jibodu, London-based musician, 1ne, and founder of sickle cell community initiative, 'The Sound of Sickle', Chris Abdullhai. We are also thrilled to be collaborating with our new project, Give Blood, Spread Love, to increase the online reach of our message.

Alongside the workshops above, we have been busy joining a range of organisations via video link to present our work and sign up new donors, including collaborations with several Home Office Directorates and churches and community groups in South London and beyond. We are keen to hear from you if would like to get involved in this important work and support us to sign up black-heritage donors in your communities and work places.

The need for more black-heritage blood donors remains stark; we need to continue our work to diversify the blood supply so that ethnically matched blood is available for people with sickle cell when they need it.

Blood donation takes around an hour from start to finish and is a safe procedure. Your blood donation can save or improve the lives of up to three people.



Invite us to present to your workplace, church or community group or become a Community Advocate volunteer, contact:
tracy.williams@sicklecellsociety.org

Sign up and save a life:
bit.ly/SouthLondonGives

South London Gives is funded by NHSBT

Stephanie George's Story

Stephanie, a young woman living in London, is affected by sickle cell. Following a mini stroke as a child, Stephanie initially underwent regular manual transfusions every 3-4 weeks. While regular transfusions can help to keep the sickle haemoglobin levels low, it can eventually lead to iron overload. After some initial adverse reactions, Stephanie explained how she then started a regular Automated Red Cell Exchange programme, in September 2019. Automated Red Cell Exchange is less frequently required, has a shorter procedure time and is also less associated with iron overload, so is often preferred by patients when compared to manual transfusions.

The Automated Red Cell Exchange programme Stephanie was a part of, is a collaboration between the Whittington Hospital, London and NHS Blood and Transplant's Therapeutic Apheresis team. The automated programme has been successful so far and has halved the number of visits that Stephanie has to make to hospital, with Stephanie now only attending every 6 weeks for treatment. Stephanie describes the Nurses who provided her treatment as attentive, supportive and compassionate.

Living with this condition, Stephanie explained, has developed her strengths as an empathetic and compassionate person. In turn, this has supported her role working on the front-line of the NHS, as a Midwife. In a position of having seen the NHS from both sides, as both a patient and a care-provider, Stephanie explained that she has more of an understanding of the pain that others are going through when they are under her care.

With new research every day, Stephanie is hopeful that there will be an improved understanding of her condition and that the treatment options available will continue to develop further.

Additional information:

Therapeutic Apheresis treatment uses a cell separator machine to add or remove constituents of the blood, such as red cells, white cells or plasma. A procedure tailored to the patient's needs can treat many other diseases such as cancer and nerve conditions. NHS Blood and Transplant provide therapeutic apheresis services to adults and children across England. Treatment is provided by teams of expert nurses and doctors who provide both elective and emergency (24/7 365 days per year) treatment to patients. For more information on therapeutic apheresis services or on how to access treatment please email TherapeuticApheresisServices@nhsbt.nhs.uk or visit our web pages: https://www.nhsbt.nhs.uk/what-wedo/diagnostic-and-therapeuticservices/therapeutic-apheresis/

Approximately 60% of all sickle cell patients in England require a special type of blood product called Ro subtype. On average, 8 units of blood (adults)/7 units of blood (children) are used to support every Automated Red Cell Exchange treatment. NHS Blood and Transplant are urgently trying to recruit more black donors to support patients with sickle cell. One blood donation takes approximately one hour from start to finish and can save up to three lives. If you or your family would like to donate, please visit www.blood.co.uk

SCS letter to Boris Johnson on Public Health England Restructure

Letter to Boris Johnson urges the Prime Minister to not lose smaller charity partnerships in Public Health England restructure.

John James OBE, Chief Executive of the Sickle Cell Society (SCS) has sent a letter to the Prime Minister, urging him to not lose valuable partnerships with smaller charities and the world leading-services those partnerships provide, when considering the restructure of Public Health England (PHE).

Recently, over 70 health organisations have written to the Prime Minister with concerns about the future of PHE. Included in these 70 organisations are some of the largest health charities in England. However, the SCS has written to make sure that smaller charities are also included in all future plans, to ensure that world-leading screening services supporting people living with sickle cell disease and diverse communities, can continue.

The letter explains that sickle cell (an inherited blood disorder affecting around 15,000 people in the UK) is currently a perspective that is missing from the debate despite the UK being a global leader in regards to a national screening programme for sickle cell.

The sickle cell screening programme leads the way for screening programmes across the globe. The programme is run by PHE and its strength comes from the close and effective collaboration with patients and the SCS, as this ensures that the screening programme is meeting the needs of those at particular risk of sickle cell. It is through this collaboration that the programme has been recognised as a world leader.

The letter urges the Prime Minister to ensure that this decades-long collaboration and world leading service is not compromised because of the PHE restructure, in favour of other high profile public health priorities.

Smaller charities play a crucial role in health care in England, providing valuable insight and support for PHE as well as representing diverse communities which are often ignored. It is vital that the restructure of PHE must consider their contribution to the public health agenda.

Boris Johnson MP
Prime Minister
10 Downing Street
London
SW1A 2AA

SICKLE CELL SOCIETY
54 Station Road
London NW10 4UA

T 020 8961 7795/4006
F 020 8961 8346
E info@sicklecellsociety.org
W www.sicklecellsociety.org
Social Media @SickleCellUK

17 September 2020

Dear Prime Minister,

There has been much comment about the abolition of Public Health England in the last few weeks.

Over 70 Health organisations have written to you including the Richmond Group of Health and Care Charities.

We are not part of the Richmond Group but we do have another perspective to that expressed by those august Health and Care Charities. It is a perspective that is missing from the debate but one that is very important for diverse communities particularly those at risk of sickle cell disease (SCD) and smaller charities.

The UK is a global leader with regard to a national screening programme for sickle cell disease (SCD), something that should be celebrated and built on. A strength of SCD screening as run by Public Health England is the close and effective collaboration with patients and the Sickle Cell Society to ensure that the screening programme is meeting the needs of those at particular risk of sickle cell disease. This collaboration has contributed to PHE being recognised as a world leader in screening programmes. Although many organisations support working with service users, PHE are rare in making this a meaningful and dynamic collaboration that is well received by patients and clinicians alike.

SCD is the most common genetic blood disease in the UK /globally but always has to fight to be included in NHS priorities. The narrative around the abolition of PHE misses a lot of the value of the organisation working with small charities on rare conditions as well as the impact for diverse communities. We do not want the good work that the collaboration between PHE and our organisation has achieved in tackling health inequalities, over many decades to be compromised or risked because of the PHE restructure or missed in favour of obesity, smoking and other high profile public health priorities. Small charities like ourselves are incredibly vulnerable, particularly in this economic and political turmoil. The restructure of Public Health England must consider our contribution to the public health agenda and the diverse communities we serve. I therefore seek your assurance that this will be the case

Yours Sincerely

John James OBE
Chief Executive
Sickle Cell Society

41st Annual General Meeting (2020)

The 41st Annual General Meeting (AGM) of the Sickle Cell Society took place on Wednesday 9th September. In view of the Covid19 pandemic this was our first ever virtual AGM meeting.

We were encouraged with virtual participation from members with the recent virtual events we have held about the impact of Covid19 on the SCD community. We were therefore delighted and honoured to have our members and stakeholders attendance at this virtual event.

The AGM was opened by Chair of Trustees, Kye Gbangbola, who welcomed members, ran through the minutes of the previous AGM and introduced the annual report.

This was followed by co-chair and treasurer, Michele Salter, leading members through the audited accounts and explaining the financial situation of the Society.

The floor was then opened to members for a time of questions and answers, before the official AGM was closed.

Iyamide Thomas then introduced the Emmanuel Amuta Poetry Award, announcing the winners and reading out the 1st prize poem by winner Ariana. We then heard from Ariana's parents.

The meeting finished with a vote of thanks.

A massive thank you to everyone who attended. All the AGM documents, key links discussed during the meeting and the full recording can be found at our website: https://www.sicklecellsociety.org/agm20/

Clockwise: Kye Gbangbola (Chair of Trustees), Michele Salter (Co-chair and Treasurer), John James OBE (Chief Executive) Nathan Hepburn (Trustee)

Emmanuel Amuta Poetry Award

The Emmanuel Amuta Poetry Award is a creative competition for young people (between ages 10 -15 years) who have sickle cell. The award has been created in memory of Emmanuel Amuta who suffered from sickle cell and sadly passed away on 19 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 the winners were announced at our first ever virtual AGM on 9th September 2020. You can see the winners and their amazing poems below:

1st Prize (winning £50): Ariana (Age 11)

The Sickled Warrior

Sickle cell does not mean
I have to live in a lonely shell
I can flourish and prosper
Like a jingling bell
I can be amazing
Like no one can tell
I have wonderful carers
That help me keep well

This disorder is a challenge
That I daily overcome
It is common
In the part of the world that I come from

If it's what I want
A dancer I shall be
If it's what I want
A doctor will be me
If it's what I want
A marine biologist I shall be
But guess who sickle cell can't hold back
That's right, you and me

2nd Prize (winning £30): Zoya (Age 10)

Sickle Cell and Me

I love my little life.
Living as carefree as a 10 year old can be!
Running for miles,
Skipping through tall grass
Swimming in beaches
And playing with as much snow as the eye can see
But …

All of a sudden, things become insane
My lungs begin to wheeze
The cold from the snow makes me freeze
And my body is filled with pain

I get stuck in hospital because of my oddly shaped blood cell
Morphine enters my brain and everything is fuzzy and weird like mud
My little life isn't always filled with glee
But ..
It won't stop me!
I'll run for miles and know when to stop
I'll swim in beaches until the temperature drops
I'll play with snow and know what my limitations shall be
I will keep on living my little life
Still filled with glee
Still happy and carefree
With my sickle cell and me.

3rd Prize (winning £20): Asi (Age 14)

Sickle Cell Poem

Sickle Cell
It makes me so unwell
How I wish
It didn't exist

Medicines upon medicines
The hospitals
The appointments
No variance
You know the drill

The drips
The needle tips
The vein that can never be found
They jab and stab,
They price and poke
Seriously? It's not a joke.

On comes the pain
I wonder how I'm still sane
Some days I feel fine
But on others, it's crossed the line

One minute you're fine, the next, God knows what.
Some days I feel so weak
But all I wanna feel is chic.

It might sound crazy,
But there are positives
I've met great, inspiring people
And I've made lifelong friends
Like you.

At the end of the day,
We can look in the mirror
And say
We are Sickle Cell Warriors.

SCS Chief Executive, John James OBE, appears in Leaders Council podcast alongside Lord Blunkett

The Sickle Cell Society's Chief Executive, John James OBE, appears in Leaders Council podcast alongside Lord Blunkett.

The Leaders Council of Great Britain and Northern Ireland is currently in the process of talking to leadership figures from across the nation in an attempt to understand this universal trait and what it means in Britain and Northern Ireland today.

John James OBE was invited onto an episode of the podcast, which also included an interview with Lord Blunkett. Host Scott Challinor asked both guests a series of questions about leadership and the role it has played in their careers to date.

Scott Challinor commented, 'Hosting a show like this, where you speak to genuine leaders who have been there and done it, either on a national stage or within a crucial industry sector, is an absolute honour.'

Lord Blunkett, chairman of The Leaders Council of Great Britain and Northern Ireland said, 'I think the most informative element of each episode is the first part, where Scott Challinor is able to sit down with someone who really gets how their industry works and knows how to make their organisation tick. Someone who's there day in day out working hard and inspiring others. That's what leadership is all about.'

You can listen to the podcast in full here: http://www.leaderscouncil.co.uk/members/john-james

New Trustees

Mr Shubby Osoba, MBA

I am a Solicitor, Entrepreneur and a Sickle Cell Warrior.

I have always been actively involved in charitable activities, however I recently decided that I had to turn my energy and attention towards helping others with sickle cell, and I am therefore very proud and excited to be appointed as a trustee of the Sickle Cell Society.

I look forward to using my personal experience of managing the condition, along with my professional skills, expertise and enthusiasm to help the charity continue to grow and have a positive affect on the lives of people with sickle cell, their friends and families, throughout the UK and beyond.

I feel that with the technology available to us now, we have an amazing opportunity to let our voices be heard, and develop a knowledge based community that enable us to support each other more than ever before.

With love and strength!

Mr Nathan Hepburn

I am a civil servant with a real passion for making a difference. I have previously worked for the FCO, Home Office and Department for International Trade, I am currently working in the Department of Health and Social Care on Reciprocal Healthcare.

I attended the 2019 Sickle Cell Society Children's Holiday and 40th anniversary gala and was so inspired by the difference I felt the society was making that I leapt at the chance to further work to support the Society.

CORONAVIRUS (COVID-19) AND SICKLE CELL LIVE Q&A

With the increase of coronavirus and the beginning of shielding back in Spring, we were seeing a large increase of questions and calls for information and support. We decided to join with our medical advisers for a Live Q&A to answer questions and provide guidance.

The first Live Q&A took place on Friday 15th May 2020 at 3pm-4pm. It was attended by people from across the country who asked questions around sickle cell and coronavirus to our expert panel.

The panel consisted of John James OBE (Chief Executive of the Sickle Cell Society) and June Okochi (Head Of Program Management at NHS West Essex CCG, and Lead Mentor of SCS Mentoring Programme).

Unfortunately we had some technical issues so other panel members Professor David Rees (Consultant Paediatric Haematologist and SCS Medical Adviser) and Dr Kofi Anie (Consultant Psychologist and SCS Medical Adviser) were not able to join us.

The second Live Q&A took place on Friday 5th June 2020 at 4pm-5pm. We had figured out the technical issues so we were able to have a larger panel consisting of John James OBE, June Okochi, Professor David Rees, Dr Kofi Anie and Dr Mark Layton (Consultant haematologist and SCS Medical Adviser).

Our third and most recent Live Q&A took place on Friday 11th September, 4pm-5pm. It was attended by people from across the country who asked questions around sickle cell and coronavirus to our expert panel including John James OBE, Professor David Rees, and Dr Kofi Anie.

This Live Q&A also saw presentations on 'Clinical Experience Perspective' by Keisha Osmond-Joseph, 'Experience of Shielding and coming out of lockdown' by Zainab Garba- Sani and the 'UCL Covid-19 Research Study' by Professor Fenella Kirkham & Anna Hood, Ph.D.

You can watch the recordings of all three Live Q&As at our YouTube channel: www.youtube.com/c/SickleCellSocietyUK/

Haemoglobinopathies Coordinating Centres (HCCs)

As you may remember as part of the Sickle Cell Service Review (Haemoglobinopathy Service Review) part of the proposed changes were the introduction of Haemoglobinopathies Coordinating Centres (HCCs).

HCCs are responsible for coordinating, supporting and promoting a system-wide networked approach to the delivery of haemoglobinopathy services. HCCs aim to support hospitals in their area who have less expertise in these conditions, to make sure all patients have access to specialist advice when needed. This will involve offering training and advice to less experienced hospitals.

Below is the full list of Sickle Cell Disease Haemoglobinopathies Coordinating Centres (HCCs):

North West: Manchester University NHS Foundation Trust
North East and Yorkshire: Sheffield Teaching Hospitals NHS Foundation Trust
East Midlands: University Hospitals of Leicester NHS Trust
West Midlands: Contract currently being finalised with Trust – updates to be added
East London and Essex: Barts Health NHS Trust
South East London and South East: King's College Hospital NHS Foundation Trust
West London: Imperial College Healthcare NHS Trust
North Central London and East Anglia: University College London Hospitals NHS Foundation Trust
Wessex and Thames Valley: Oxford University Hospitals NHS Foundation Trust
South West: University Hospitals Bristol NHS Foundation Trust
You can see the full list of HCCs including sickle cell and thalassaemia, the National Haemoglobinopathy Panel (NHP), and Specialist Haemoglobinopathies Teams (SHTs) here: www.sicklecellsociety.org/hccs/

Sickle Cell Awareness Month - Darien's Story

To mark Sickle Cell Awareness Month UK (July) brave 9 year old Darien who attends Central Middlesex Hospital at London Northwest University Healthcare NHS Trust tells us what it's like to live with sickle cell.

"As I am writing about my experience, it has been 12 weeks since the lockdown, and since then I have been at home shielding from the Covid-19 pandemic with my parents and sister.

I was scared at first because I have sickle cell and knew I was more of a risk of getting it after listening to the news and the government saying thousands of people would die. One of the reasons I was scared was because I already had pneumonia last year in Jamaica and was in the hospital for two weeks and I heard on the news that pneumonia was a symptom.

I am 9 years old and living with sickle cell. I live a normal life knowing I have the disease. I can remember getting sick three times in my life. I eat foods that keep me healthy, especially foods that are rich in iron such as liver and green bananas. I also drink a lot of water to keep my eyes from becoming yellow (jaundiced) and it keeps me feeling well. I also go outside so I can exercise and get to play as it also expands my lungs.

Having sickle cell has not stopped me from doing the things I love such as playing sports, playing with friends and travelling the world which I enjoy.

Since taking hydroxycarbamide I have noticed the difference with my growth. My family keeps saying also that I have grown a few centimeters taller. This made me happy because at first I could see that I was shorter than the kids in my year group. I am really happy that schools are opening so I can see if I've caught up to my friend's height.

The main thing to remember about living with sickle cell anemia is to eat healthy, drink plenty of water and exercise!"

Find out more about the London Northwest University Healthcare NHS Trust here: **www.lnwh.nhs.uk**

FUNDRAISING SPOTLIGHT

We rely on your kind donations and fundraisers to keep doing the work we do. Every donation and fundraiser allows us to reach more people, run more activities, and improve the lives of those living with sickle cell.

We want to say a massive thank you to everyone who has created a fundraiser to support our work. Some of the fundraisers below are still raising money so their totals may change.

A massive thank you to Newline Group (part of the Odyssey Group) for their donation of £3000 and to Nathan Drummond for nominating us! Your support is deeply appreciated!

A huge thank you to The Rochester Grammar School for raising £1,674 for their Founders Day fundraiser.

A big thank you to James and Charlie for running fun maths taster sessions and for raising £70 as part of their Maths Challenge.

A massive thank you to Team Sparrow for their Showing up for Sickle Cell fundraiser for raising £1,314.

A big thank you to our new trustee, Nathan Hepburn, who shaved his hair and raised £300.

A big thank you to Kate Redhead for raising £520 by running 200km in memory of her father-in-law, Cuthbert Redhead.

A huge thank you to Marvin Samuels and his wife for raising £450 in memory of Edward Alder, by cycling 200 miles during July.

A huge thank you to Community Pardner CIC for raising £1,230 in August.

A massive thank you to Nigerian Healthcare Professionals UK for raising £783.36 in June

A huge thank you to Rinse FM radio and Fabio & Grooverider for raising £362 with their 24 hour music live stream

Thank you to all of our Facebook Fundraisers for raising money for us, with a special thank you to Samir and Mikey, Tonye Porbeni Adensui and our patron Elizabeth Anionwu who were our top fundraisers.

A massive thank you to Richard Patching for being one of our first fundraisers for the Two Point Six Challenge and raised £430.

A massive thank you to Shareefa J and the whole Shine 4 Diversity team who ran the Official Big Half back in March and raised £520.

A big thank you to Ayodeji Akande for raising money for us over a whole range of fundraisers including: London Big Half Marathon, Milton Keynes Festival of Running, Manchester Marathon and Race To The Stones (100k).

A massive thank you to Black Women in Health [BWIH] for organising a virtual charity event and raising £1,232 to support our work.

A huge thank you to EvRy Events by Salt for marking World Sickle Cell Day with a Balloon Challenge fundraising raising £1,035.

A big thank you to Tonye Adenusi for raising £1360 by shaving her hair off.

A huge thank you to Anita Romer and family who have raised £249 to support our work in memory of Kemi Akintoye.

A massive thank you to Zach Chambers who has raised £1,359 by cycling the length of Route 66 virtually - a massive 3669km from start to finish over 84 days.

A massive thank you to Lloyd Crowley and the Ware Ukulele Group who raised £2,325 in memory of Baz Thorne.

A massive thank you to the Leicester Kids COVID Relief Cycle Fundraiser, a group of 5-17 year-olds who rode 10km each and who have raised £4,834.19 for us and three other charities.

A big thank you to the Marching against Sickle Cell team for raising £1,621 by walking over 200 miles from central London to Dartmoor National Park.

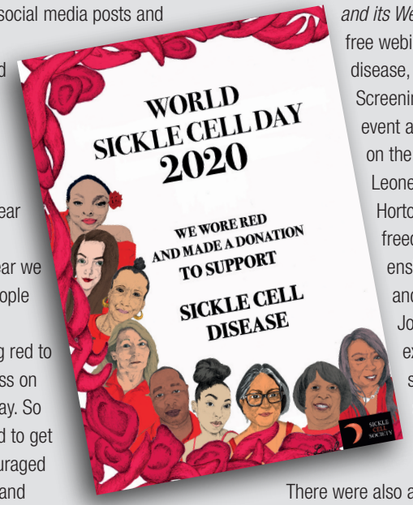
World Sickle Cell Day

On the 19th June we celebrated World Sickle Cell Day. World Sickle Cell Day is a United Nations recognised day to raise awareness of sickle cell at a national and international level. On 22nd December 2008, the United Nations General Assembly adopted a resolution that recognises sickle cell as a public health problem and "one of the world's foremost genetic diseases." The resolution calls for members to raise awareness of sickle cell on June 19th of each year at national and international level.

Raising Awareness

This year we celebrated with a 'Did You Know' social media campaign, sharing key facts about sickle cell and raising awareness. As well as graphics, we also created an awareness video '10 Facts About Sickle Cell Disorder'.

We wanted to get as many people involved on World Sickle Cell Day, so we created a whole range of graphics, social media posts and facts which people could download and share for free with their friends, colleagues and families.



We also ran a Wear Red for Sickle Cell campaign. Every year we had seen lots of people posting pictures of themselves wearing red to help raise awareness on World Sickle Cell Day. So this year we wanted to get involved, and encouraged staff, stakeholders and members to put on red clothes and join in with raising awareness. It was brilliant to see people from around the world wearing red and sharing facts and information, including our patron, Eastenders actress, Ellen Thomas.

Events

On top of raising awareness, we also ran and took part in a range of events on and around World Sickle Cell Day.

On 19th June, our Chair of Trustees, Kye Gbangbola was a panelist for *Current Advocacy Work in Sickle Cell Disease: The Global Perspective.* The session was a free webinar run by Global Alliance of Sickle Cell Disease Organizations (GASCDO) to explore global sickle cell advocates from Africa, Europe, North America, Latin/South America, South Asia and the Middle East. The Sickle Cell Society is a founding member of GASCDO and more information can be found here: https://scdglobal.org/

On 20th June, we ran *Sickle Cell Disorders and the Call for Black Blood Donors.* The event was run by South London Gives and Our Journey, Our Story projects. The event was an interactive workshop about the history of blood donation campaigning and its importance in sickle cell disorders treatment. There were a range of speakers from the sickle cell community including Professor Dame Elizabeth Nneka Anionwu, UK's first sickle cell nurse specialist.

On 23rd June, we ran *Sickle Cell Disease and its West African Discovery*, a free webinar on sickle cell disease, its myths and the NHS Screening Programme. The event also saw presentations on the illustrious Sierra Leonean Dr Africanus Horton, whose parents were freed enroute to being enslaved in the Americas and on our project (Our Journey, Our Story) exploring the history of sickle cell in the UK since the arrival of the 'Windrush Generation'.

There were also a whole range of fundraising events and campaigns including a Wear Red campaign. Real Lives blogger and sickle cell advocate, Laurel Brumant Palmer, took on the challenge with a unique twist: each person who donated to her fundraiser on World Sickle Cell Day and wore red to raise awareness would be added to a hand drawn awareness poster. To date, the fundraiser has raised £380 and today the beautiful poster was completed.

We want to say a massive thank you to everyone who got involved in raising awareness this World Sickle Cell Day.


Lee (from the US)

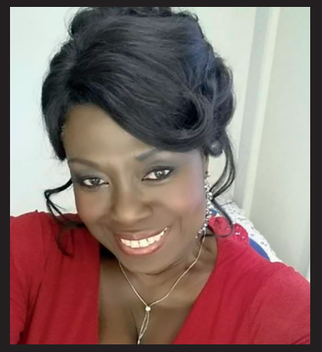
Michelle (SLG Community Advocate)


Ade (from Gambia)

Viv (SLG Community Advocate)


Matthew (Communications and Social Media Officer SCS)


Angella


Ellen Thomas (Actress, SCS Patron)


Francis and his Mum Jannette (from Sierra Leone)


Daphne (from the US)


Kweku (from Sierra Leone)


Kayode


Iyamide (NHS Engagement Officer)


Joanna

Bolanle (SLG Community Advocate)

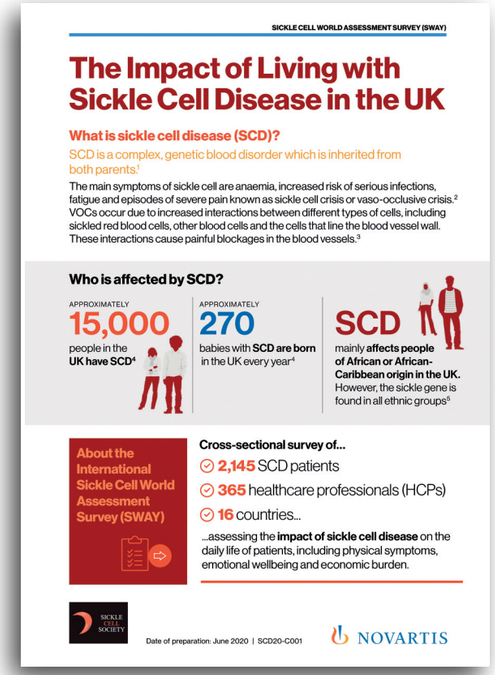

Melbourne

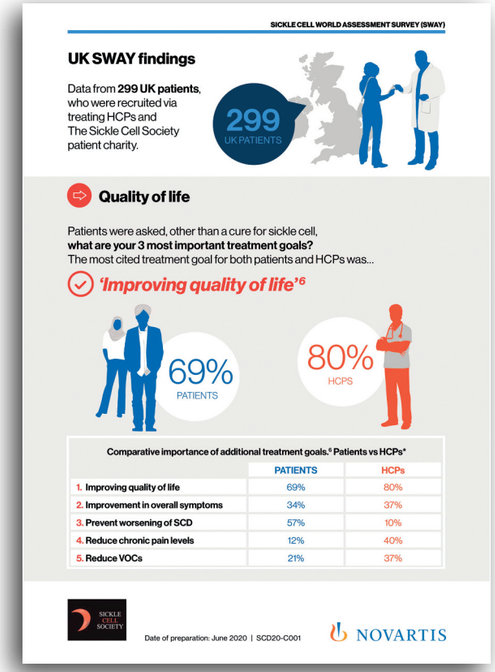
Bola (SLG Community Advocate)

The Impact of Living with Sickle Cell Disease in the UK

The Sickle Cell World Assessment Survey (SWAY) is one of the world's largest sickle cell disease surveys, supported by an international steering committee of medical experts and patient advocates.

SWAY collected insights from more than 2,100 patients (200 of which came from the Sickle Cell Society) and 300 health care providers from 16 countries to evaluate the impact of the disease on patients and families and help inform the management of this life-long condition. Results were presented at the 2019 American Society of Hematology (ASH) Annual Meeting.





Petition

Ara Erinle has created a petition calling the government to '*Include Sickle Cell Anemia in the List of Illnesses Eligible for a MedEx Card*' enabling people living with sickle cell to get free prescriptions.

So far the petition has received almost 28,000 signatures. At 10,000 signatures the petition received a response from the Government saying that they have "no plans to make changes to the list of medical conditions exempting patients from prescription charges".

At 100,000 signatures the petition will be considered for debate in Parliament, so please sign and share: **bit.ly/medexsurvey**

Prescription Charges

The Society continues to work on getting free prescriptions for people living with sickle cell both through the Prescription Charges Coalition and the Sickle Cell and Thalassaemia All-Party Parliamentary Group.

The Prescription Charges Coalition are a group of 48 organisations (including the Sickle Cell Society) calling on the Government to scrap prescription charges for people with long-term conditions in England. You can find out more about our work with the coalition here: **www.prescriptionchargescoalition.org.uk/**

The All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG) aims to be the voice in Parliament of Sickle Cell and Thalassaemia patients and their families. We campaign on multiple issues, including patient experience and workforce. Members achieve this aim by engaging with parliamentary colleagues, the government and health professionals to raise awareness relating to the conditions and needs of patients.

The SCTAPPG continues to work on this issue following our report 'End the Blood Tax' an investigation into the impact of prescription charges for those living with sickle cell and thalassaemia, published last year. Find out more about this work here: **www.sicklecellsociety.org/sctappg/**

Global's Make Some Noise raises over £40K for Sickle Cell Children's Activities Programme

The Sickle Cell Society is excited to announce that in April, Global's Make Some Noise has raised £44,385 for our Children's Activities Programme!

Last year, the Sickle Cell Society was chosen to be a Global's Make Some Noise charity alongside 32 other small charities and projects across the UK.

Global's Make Some Noise is the official charity of the Media & Entertainment group Global, home to some of the UK's biggest radio brands including Heart, Capital, Classic FM, Smooth, LBC, Radio X, Capital XTRA and Gold.

Over the past year, the Global's Make Some Noise team having been raising money and awareness for sickle cell and the other charities.

On the radio – the Sickle Cell Society were delighted to be invited to speak about sickle cell on the radio. A young girl named Miai was able to share her story about living with sickle cell on Capital FM

Training – members of the Sickle Cell Society staff were able to receive training from Global's experts

Fundraising – the main goal of Global's Make Some Noise has been raising money through radio fundraisers to support a whole range of projects

The total money raised over the past year will fund 41 roles over the next 12 months and will help charities (including the Sickle Cell Society) working with: bereavement and trauma, young carers groups, disability, life-limiting or life-threatening conditions, music therapy, care leavers, mental health.

The £44,385 that the Sickle Cell Society received will go to fund our Children's Activities Programme, supporting children and young people living with sickle cell.

The Sickle Cell Society wants to say a massive thank you to the whole Global's Make Some Noise team and everyone who has donated. We have seen the amazing impact our children's work has had in the past and this money will help us to reach even more children and young people.

Suki's Story – Blood Donors Save My Life

Mum of one of the youngest sickle cell patients to rely on donated blood makes emotional appeal for more black donors.

Children like 17-month-old Suki urgently need better matched blood to give them the best possible start in life.

The mum of a toddler who needs regular blood transfusions to stay alive is urging more black people to donate to help patients like her daughter who need ethnically matched blood.

Layla Lawson's 17-month old daughter Suki has sickle cell disorder, an inherited blood disorder that is more common in black people. It can cause organ failure, stroke or loss of vision, and can be fatal.

Layla and Suki as part of the Blood Donors Save My Life campaign

It is estimated that fewer than one in 10 of the 4,000 children and young people with sickle cell in England* are on the transfusion programme, making Suki one of the youngest to depend on life-saving blood donations. Other children with the disorder still need blood in emergency situations.

Many adults rely on frequent transfusions to reduce the risks from sickle cell but children are typically able to manage the disorder with medication. They are more likely to need blood for treatment as they become older, as the risk of serious and life-threatening complications increases with age.

"Every day is a worry when you have a child with sickle cell. If more black people gave blood, I would have less worry about transfusions exposing Suki to other complications."

"To people from a black background I just want to say 'please, donate blood'. You will help secure the future of children and adults with sickle cell who depend on blood – you will save lives."

Sickle cell affects the red blood cells that carry oxygen around the body. These cells form into a sickle or crescent shape and can block blood vessels, causing agonising pain and creating a risk of life-threatening complications. This is known as a sickle cell crisis.

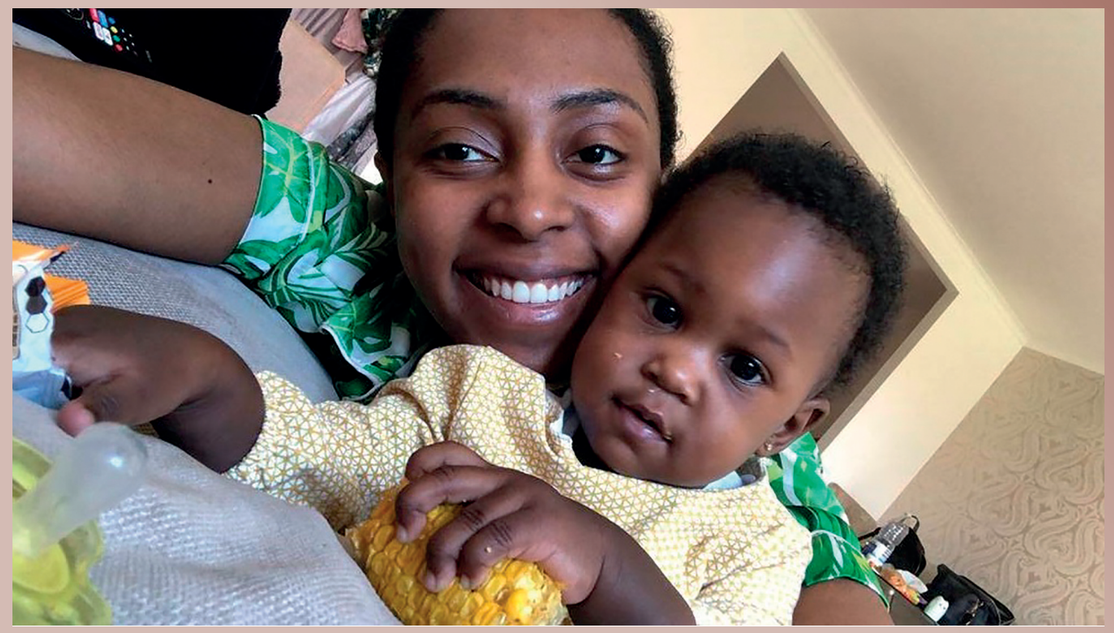
Many of the 14,000 sickle cell patients in England need regular blood transfusions or exchanges to help prevent or relieve the painful symptoms and complications. Others rely on blood for emergency treatment if they experience a crisis.

Without matching blood, patients risk complications caused by their transfusions and currently sickle cell patients are the most vulnerable to this due to the shortage of black donors.

While the number of black blood donors has grown steadily in recent years, the urgent shortage remains. There are currently 12,633 black and mixed black donors, which is around 1.5 percent of the donor base.

"Blood donors are vital to saving the lives of many people living with sickle cell. We are working hard to ensure we see an increase of black heritage blood donors signing up to make a difference." – John James OBE, Chief Executive, Sickle Cell Society.

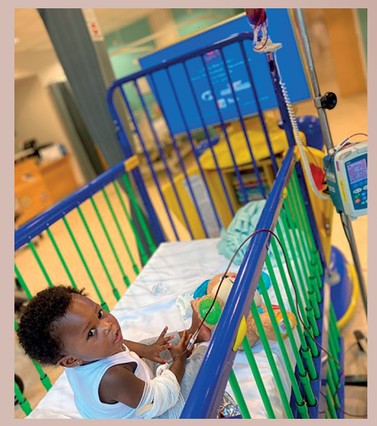
"More and more black people are saving lives by donating blood. But the NHS urgently needs more black donors so patients like Suki can receive the best matched blood possible. Blood donation is quick, easy and safe. We urge people of black heritage to do something amazing and register as donors. You will save lives." – Nadine Eaton, Head of Blood Donor Recruitment for NHS Blood and Transplant.



Since the covid-19 outbreak extra safety measures have been introduced across all blood donation sessions. On arrival donors have their temperature taken and are triaged to ensure only those with no risk factors can enter.

Hand gels and hand washing facilities are available inside donation venues, donors are spaced apart and staff are doing extra cleaning. Staff and donors are required to wear face coverings.

Become a blood donor today. Register here: bit.ly/scsgiveblood



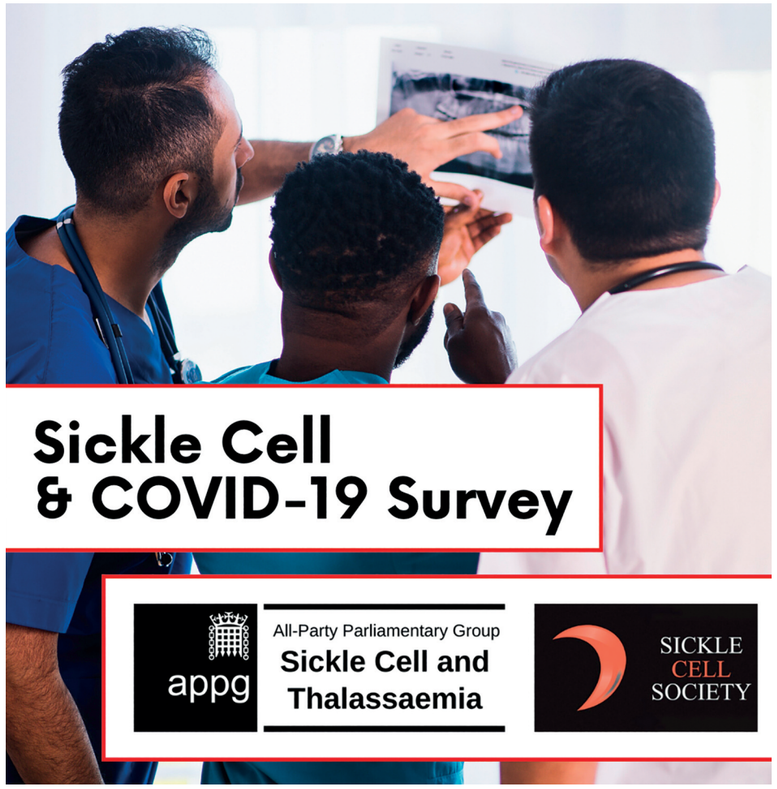
The One Show and nationwide awareness

Suki's Story is part of the Blood Donors Save My Life awareness campaign, in collaboration between the Sickle Cell Society and NHS Blood and Transplant. As part of this campaign, Suki's story has been shared on social media, in newspapers and in a special feature on BBC1s The One Show on the 6th October 2020.

1. Data from the National Haemoglobinopathy Registry shows there were 4,065 patients aged 17 and under with sickle cell registered at hospitals in England in July 2020. Data returned for 2,300 patients showed that 170 were on red cell transfusion programmes. No data was returned for 1,765 patients.

2. Ro type blood is often used to save people with sickle cell. Ro blood is 10 times more common in black people than in white people. People requiring regular transfusions need blood that is more closely matched to their own to prevent complications. This means that if a sickle cell patient has the Ro subtype, it is vital they receive blood with the Ro subtype. Only 2 percent of our donors have Ro type blood.

Sickle Cell and COVID-19 Survey



As part of our work with the Sickle Cell and Thalassaemia All-Party Parliamentary Group we have created a survey to understand the experiences of those living with sickle cell or caring for someone with sickle cell during the COVID-19 pandemic.

The objective will be to use this data to determine whether those living with/caring for someone with sickle cell disorder are receiving all the information required, and whether the guidance is suitable for their circumstances.

Thank you for taking the time to fill out this survey, it will go a long way to ensure that those living with sickle cell are receiving the treatment they deserve.

You can complete the survey here: https://www.sicklecellsociety.org/covid19survey/

Oral Sickle Cell Treatment Approved in Scotland

The Scottish Medicines Consortium (SMC) has made the decision to accept the medicine hydroxycarbamide (Xromi) for restricted use by NHS Scotland.

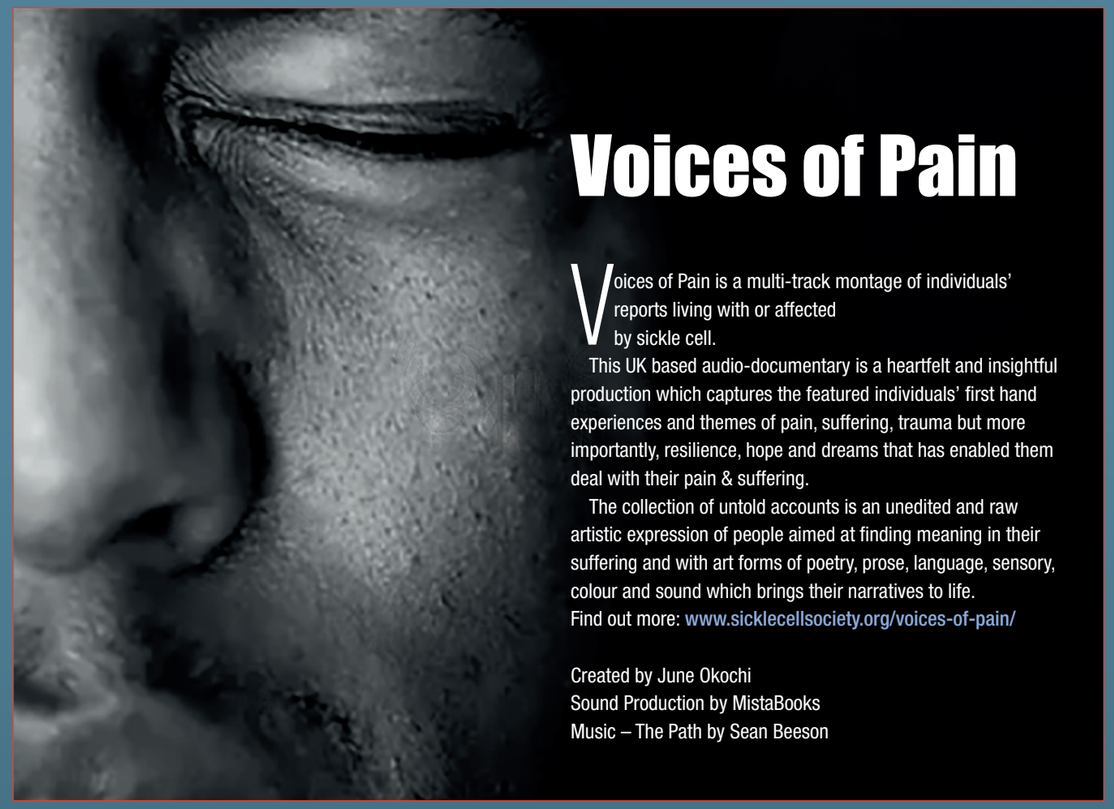
On the 10th July, the SMC completed its assessment of hydroxycarbamide 100mg/mL oral solution (Xromi), and following review by the SMC executive, advises NHS Boards and Area Drug and Therapeutic Committees (ADTCs) on its use in NHS Scotland.

Hydroxycarbamide (Xromi) is a licensed, strawberry flavoured oral liquid formulation for the prevention of vaso-occlusive complications of sickle cell in patients over 2 years of age. It is expected to be used in children under the age of 9 years who find swallowing tablets difficult.

The Sickle Cell Society worked with Nova Laboratories on their patient facing materials to ensure they were clear and easy to understand.

This is great news for the sickle cell community in Scotland and shows the promising trajectory of treatments being made available for people living with sickle cell across the UK.

Hydroxycarbamide (Xromi) is also currently available in England and Wales.



Voices of Pain

Voices of Pain is a multi-track montage of individuals' reports living with or affected by sickle cell.

This UK based audio-documentary is a heartfelt and insightful production which captures the featured individuals' first hand experiences and themes of pain, suffering, trauma but more importantly, resilience, hope and dreams that has enabled them deal with their pain & suffering.

The collection of untold accounts is an unedited and raw artistic expression of people aimed at finding meaning in their suffering and with art forms of poetry, prose, language, sensory, colour and sound which brings their narratives to life.

Find out more: www.sicklecellsociety.org/voices-of-pain/

Created by June Okochi
Sound Production by MistaBooks
Music – The Path by Sean Beeson

Become a Member

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

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/

Children's Holiday

From Friday 14th August to Sunday 16th August we hosted our first ever Virtual Children's Holiday. We have been running our Annual Children's Holiday for 8-15 year olds with sickle cell every year since the 1980s but this year, to keep everyone safe, we took our normal adventures online for the very first time! 32 families from all around the country joined us via zoom for a weekend of friendship, learning and fun.

This year the whole family took part in the holiday, not just the child with sickle cell, which was made possible by our online forum. It was fantastic to see siblings and parents getting to know one another and learning more about sickle cell too.

We got up to a whole range of activities put together by our Children's Activities Team. These included:

- Storytelling
- Tai Chi
- Yoga
- Meditation
- Arts and Crafts
- Cabin Chat
- Challenge Night
- Growing Cress
- A Scavenger Hunt
- Sickle Cell Information Sessions
- Parent to Parent Chats

We were delighted to have the help from our talented team of volunteers who helped us deliver the programme and made sure the young people had a fantastic time. Despite being virtual, the holiday was a fantastic way for families from around the country to come together over lockdown, support one another, and have some fun.

"It was an experience we will forever cherish as a family" – Parent

"I enjoyed meeting people who have sickle cell. It's nice to have friends who understand… if I have pain they know what I'm going through" – Young Person

"I really enjoyed connecting with other people who have sickle cell, I know I'm not alone. I also liked trying something new like meditation." – Young Person

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
- Support groups

During this difficult time 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. Different members of staff will be covering the helpline each day to ensure that you can get advice and support every day.

Before calling, please see the correct number to call for each day of the week and check the date as the numbers will vary week to week.

All the numbers 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**

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.

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
Telephone: 02089617795