sicklecell

SICKLE CELL SOCIETY

THE NEWSLETTER OF THE SICKLE CELL SOCIETY

AUTUMN 2022

In this issue:

An interview with North Middlesex Trust

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More male blood donors needed

Children's Holiday Recap

and much more...

www.sicklecellsociety.org

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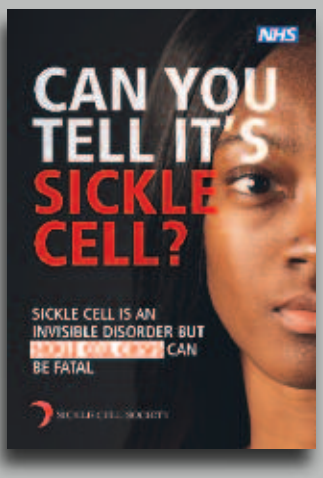


Editor Clare Rudd
Sickle Cell Society 54 Station Road London NW10 4UA
T. 020 8963 7798
E. clare.rudd@sicklecellsociety.org

It's been a very busy six months for the Sickle Cell Society, helping the Sickle Cell community navigate the changing landscape of learning to live with, but yet moving on from Covid. Events have started to move more face-to-face and we've seen a return to a "new normal".

This October we join together with our many supporters and donors in celebrating Black History Month.

I want to start this issue by saying a very big Thank You to our Chair of Trustees Kye Gbangbola who is stepping down after being a Trustee for the society since 2010. Kye has dutifully served the Sickle Cell Society for over 12 years as a trustee and then as Chair from 2014, leading the Society's overall strategy and being a passionate and avid spokesperson for sickle cell awareness.

We hugely appreciate Kye's experience, leadership and everything he has contributed to the Sickle Cell Society since his time with us. He will be deeply missed and we wish him all the best in his future endeavours.

I would like to welcome Michele Salter, our incoming Chair, who has been appointed to lead the Board of Trustees and the Sickle Cell Society in its goal to support and represent people affected by sickle cell, to improve their overall quality of life.

Michele was formerly the Vice-Chair & Treasurer and has been working hard for the Sickle Cell Society since 2014, overseeing key responsibilities such as the Society's finances and fundraising and communications strategy.

We are delighted to have Michele stepping up as Chair of Trustees. As Vice-Chair & Treasurer, she has worked

Salter

Introduction

tirelessly to support the growth and development of the charity. We look forward to seeing the Society continue to grow and reach more people under her leadership.

We are excited to welcome three new trustees to our team, Lisett Brown, Zainab Garba-Sani and Dr Kilali Ominu-Evbota. We are very excited to welcome them to the Sickle Cell Society. Our trustees play a vital role in helping the society to ensure that we are doing our utmost to support the sickle cell society. We thank them for volunteering their time and experience.

This issue, we hear from Dr Nnenna Osuji, Chief Executive of North Middx Trust as she shares how the trust has responded in the last year to last November's 'No One's Listening' report.

Our 'Give Blood Spread Love England' team has been working very hard in recent months to strike a better gender balance and encourage more males to engage with their work. Find out more later in this newsletter.

I am extremely happy to announce the relaunch of our peer mentoring programme this Autumn, running across all East London boroughs, offering support and encouragement to children and young people between the ages of 10 to 24 living with Sickle Cell within the East London area.

Our screening engagement work headed by Iyamide Thomas, gives a snapshot of range of work we are doing with the screening programme and public health England.

August saw us enjoy our third "virtual" children's holiday, moving from the in-person holidays we have run since the eighties. This summer saw our families coming together for a weekend of fun, sharing a whole host of exciting activities, education and opportunities with each other. The fantastic feedback is a testament to how much our families enjoyed their time. Take a look at some of the wonderful activities they participated in.

In this issue, we share an interview with Anusjka Regis, the first person with sickle cell disorder to have a NHS funded stem cell transplant and also hear from Aliya Gladying about her experience of living with sickle cell.

Finally, we know that the colder weather is always a difficult time for people living with Sickle Cell. This year we know that the whole country will be impacted by the energy crisis and of course very high bills, making it even more difficult for members of our community. Help and support for these issues are being made available via our website, and our helpline remains available 5 days a week from 10 am – 5 pm.

Thanks as always for your support of the Sickle Cell Society. We hope you enjoy this issue of our newsletter.

Lisett Brown *Dr Kilali Ominu-Evbota* *Zainab Garba-Sani*

Listening, learning,

By Dr Nnenna Osuji, chief executive, North Middlesex University Hospital NHS Trust

No One's Listening (Spring 2022 newsletter) set out a stark assessment of the failures experienced by patients with sickle cell disorder and thalassaemia over recent years. The comprehensive report made hard reading for everyone in the red cell community, and rightly so.

At North Middlesex University Hospital NHS Trust, where 21-year-old Evan Nathan Smith died in March 2019, the descriptions in the comprehensive report ring sadly true with what some of our red cell patients have been trying to tell us for a long time:

That some staff do not take sickle cell disorders seriously, and regard sickle cell patients as "difficult";

That patients experiencing severe pain can feel they are regarded as drug seekers, when they ask for pain relief;

That red cell services – and the patients who use them – are not given sufficient priority among the range of issues which the Trust is focused on.

I am a clinical haematologist, and since July 2021, I have had the honour to be the Chief Executive of North Middlesex University Hospital NHS Trust, which serves one of the largest populations of patients impacted by sickle cell and thalassaemia.

I have made a personal and professional commitment to the patients of North Mid's red cell service that I will deliver substantial improvements to how they experience treatment and care, both acute and ongoing. These improvements start with listening – *properly* listening, ***and*** hearing – what our patients tell us, and then taking action on what we hear to make sure our services are right and responsive to our patients, and our wider community.

As you would expect, this listening has not only already begun, but is already having a clear and tangible impact on the wide-ranging improvements we are driving forward for our red cell patients:

What we heard What we did

Our patients told us they wait too long in A&E for pain relief when they are experiencing a sickle cell crisis. We have sped up how we respond and now more than 70% of our patients are getting their first dose of analgesia within 30 minutes. We won't rest until it's every patient, every time, but I am proud of the progress so far.

Our patients said they have to wait too long for essential equipment for their care to be available, because it's shared with other patient groups and clinics. We've invested in 6 new patient-controlled analgesia machines – from 3, up to 9 – to provide patients with the equipment they need to control their pain. Staff working in our red cell service also told us that we needed to improve how we provide an apheresis service out-of-hours, so we have partnered with NHS Blood and Transplant to expand our apheresis care, which means that now patients who need apheresis out-of-hours get it with expert support from clinical staff.

Our patients are experts in the lived experience of living with a red cell disorder, and told us they want more say in shaping how their care fits around their lives, and direct dialogue with people in the Trust who can make change happen at both individual care experience level and at broader service level

We're running open listening events every 2-3 months, with red cell service patients, haematology clinical leaders, sickle cell and thalassaemia advocates and campaigners, and Trust senior managers, to ensure we're all working together on what's important to patients.

Our patients wanted the George Marsh Centre – a dedicated facility in the heart of Tottenham, long used by the sickle cell community – to be returned to service for the benefit of patients with sickle cell, thalassaemia and other red cell disorders Working jointly with a group of patients, who have generously contributed their time, views and expertise, we have refurbished the facility to become the George Marsh Centre for Wellbeing, for patients with sickle cell, thalassaemia

leading better care

and other red cell disorders. With clinic rooms for counselling and genetic testing, relaxation spaces for yoga and exercise, library and computer facilities, the renovated centre will provide a hub for patients and their families to get support for the holistic needs of their condition.

We have many more improvements in the pipeline – a new nurse consultant in clinical haematology joining us this autumn, and the refurbishment of our on-site haematology unit, which the family of Evan Nathan Smith have so generously agreed we can name after their son, so that we will be permanently living up to honouring his legacy – that I could probably fill this whole magazine. I have concentrated in this article on the improvements that will be most noticeable by patients with sickle cell disorder, but we are equally committed to improving care for our thalassaemia patients, and those with other inherited red cell disorders. One thing I can assure readers is that we will work in true partnership with patients, ensuring their voices resonate through everything we do.

We are fortunate to have a vibrant and interested local community in the heart of north London, and honoured that so many of our patients and their families are willing to 'lean in' and help us improve. I know that some of these improvements have been overdue for some time, and I am fully committed to making up and getting ahead on the timeline for delivering the very best standards of care for our red cell patients. We are privileged that the Sickle Cell Society is prepared to help hold us to account for what we have said we will do, and look forward to your continued challenge to be the very best for our red cell patients.

UPDATE

Screening 'Engagement Project'

Iyamide Thomas, NHS Engagement Lead, Sickle Cell Society

First, A Project Recap!

On 1 August 2022, we commenced 'Year 5' of an 'Engagement Project' commissioned by the NHS Sickle Cell and Thalassaemia Screening Programme 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. (Now you know where my 'NHS Engagement' title originates from!). This collaboration is important as the two Societies are the interface between the Screening Programme and its users, working flexibly with communities affected by sickle cell and thalassaemia in a culturally sensitive way, gaining trust and useful insights. The Societies are thus able to inform the Screening Programme's policy and practice and help them address any existing inequalities in their service delivery.

World Sickle Cell Day

Each World Sickle Cell Day of 19 June, the Sickle Cell Society raises awareness (we do this throughout the year by the way), sometimes with the '*wear something red*' theme. Yes you've guessed it, this is why I chose that profile picture for my article! We also produce special graphics which we share on social media to highlight data obtained from newborn screening.

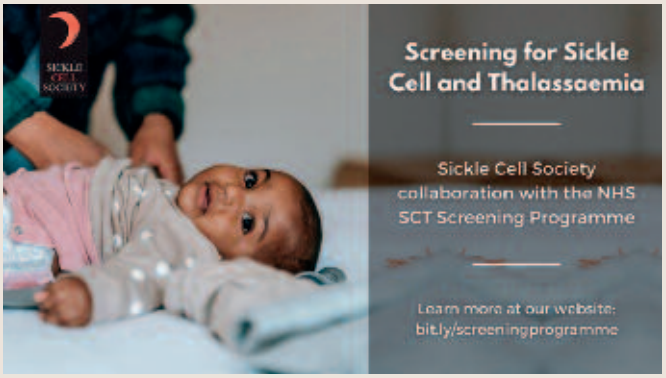
Men No Longer Wanted – Yet!

Well at least not for the focus groups I was recruiting for last time, as I'm happy to say I recruited five men to discuss their views on the communication of newborn screening results! This valuable focus group feedback from mothers, fathers and individuals who are not yet parents will form the basis of a new publication '*Parents Stories -2'* and more importantly, feed into the Screening Programme's review of their '*Protocol for Reporting newborn screening results for sickle cell disease to parents'* targeted at health professionals, which was last updated a while ago. This will show how people at-risk of carrying the sickle cell gene are being consulted via the Societies and are subsequently influencing Screening Programme policy.

With the help of Professor Karl Atkin and Dr Maria Bergh (who are members of the Engagement Project Advisory Group), Sickle Cell Society and UK Thalassaemia Society and the Screening Programme have begun analysing the transcripts of the focus groups. Some very rich data is already coming out. We've broken this down to themes and sub-themes, such as Diagnosis (parents views when told baby had SCD / trait), Pathway in Screening, Disclosure, Access, Knowledge and Understanding. We plan to launch *Parents Stories -2'* and the revised '*Protocol for Reporting newborn screening results for sickle cell disease to parents'* at a conference in April 2023, so watch this space!

E-Learning Resource

The Screening Programme is continuing work on updating their e-Learning resource for health and other professionals working in the screening pathway, which both SCS and UKTS are feeding into as user views are an integral part of the quality assurance process and ensuring inequalities are addressed.



Non-clinical information of healthy living with sickle cell and thalassaemia is currently being added and this revision will be sent to the Societies for comment. The videos recorded by SCS /UKTS will also be part of the resource, showing the collaborative work we do with the Screening Programme and some of the cultural issues the Programme needs to consider when delivering its service.

Review of Screening Programme Standard 5

The Screening Programme has a set of standards which are used to monitor performance. They are currently reviewing Standard 5, which is the timely offer of prenatal diagnosis to women at risk of having a baby with sickle cell or thalassaemia. SCS / UKTS and the Project Advisory Group have given comments on this. Currently Standard 5 is reported in 2 parts: S05a (women at risk), and S05b (couples at risk) however, this risks women being counted twice. The proposal is to have one standard and remove the word 'couples'. The review continues as the timely offer of prenatal diagnosis is important since a late prenatal diagnosis of an affected foetus can reduce parents' choice to terminate a pregnancy in certain cultures /religion.

Outreach

Outreach is a continuous work-stream of the project and the SCS and UKTS use their respective networks to raise awareness to the public and health professionals on screening issues as well as general awareness of sickle cell and thalassaemia. Since the last update I have done a variety of talks including to the general public in churches and also brought the screening perspective to 'Invisible Warrior' workshops on Improving Patient –Doctor Relationship' and 'Current and future SCD Treatments'. Both Societies presented their work to three forums for health professionals in the screening pathway (e.g midwives). We are now designing a 'preconception strategy'; for young adults who have not yet had children, giving them information on preconception testing and the various options available to couples with the trait.

'Preconception, Antenatal, Newborn and Maternity' Task and Finish Group

Recently, as a result of the Sickle Cell Society's *'No Ones Listening'* Report produced at the end of last year, the NHS England and NHS Improvement (NHSEI) are reviewing the Sickle Cell Pathway so as to improve user experience and address existing inequalities. I was part of the Task and Finish work stream for **'Preconception, Antenatal, Newborn and Maternity**'. All workstreams are complete and will be producing a report. I have now also been asked to join the related Patient Advisory Group.

PERICLES (Prenatal Therapy for Sickle Cell Disease)

I represent the SCS on a King's College related research project called 'PERICLES,' which is seeking to find out stakeholder views and attitudes towards Prenatal Therapy for sickle cell disease, a future treatment using stem cell transplant which will effectively cure affected babies in the womb. We have now finalised a short recruitment video and plan to start recruitment in October. We will be needing participants for interviews. For more information please visit the project website: https://www.kcl.ac.uk/research/pericles

Once again, this update gives you an overview of progress with the Engagement Project (mainly from the Sickle Cell Society perspective) 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/screeningprogramme/

Excerpt from forthcoming recruitment video

A scene captured in the E-resource video of Iyamide's outreach in barber shops

WEAR RED FOR WORLD SICKLE CELL DAY

Thanks to all those who sent wonderful pictures of them wearing Red for World Sickle Cell Day on the 19th June to help raise awareness of Sickle Cell. We appreciate your support! Photos not featured here were featured in our social media

All Saints New Cross

Dipo UK

Daphne -USA

Ade-Gambia

Hassan-UK

Ibi UK

Iyamide

John-UK

Kayode-UK

Margaret-UK

Melbourne -USA

Mohammed UK

Nick-UK

Lynette -UK

Dr Rachel Kesse-Adu (right)

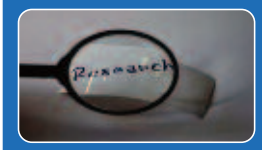
Dorcas-UK

Umu-UK

Gloria-UK

ASCELUS SERVICE USER ADVISORY GROUP – INFORMATION SHEET

UNIVERSITY OF LEEDS



WHAT IS THE RESEARCH ABOUT?

- The research is about a new way of helping patients manage blood disorders that is called Ascelus. This uses the internet or a smartphone to link patients to hospital staff who are involved in their healthcare
- We want to find out how Ascelus can include patients who may not feel entirely comfortable with using digital communication.

WHAT WILL THE ADVISORY GROUP DO?

- Group members will discuss their experience of using the internet and smart-phones and any problems - such as understanding what to do or the costs involved
- They will also meet with people involved in the research to hear about what they are doing and to influence how they can make Ascelus as easy to use as possible

WHAT TO EXPECT

- 3-4 meetings a year to make recommendations for the research
- Reimbursement for your expenses and time
- Training and personal development opportunities
- Opportunities to be involved in other activities linked to the research

FURTHER INFORMATION

If you would like to know more about the research or Advisory Group please contact:
Dr Ghazala Mir, University of Leeds - email: g.mir@leeds.ac.uk Tel: 0113 3434832
Text 07765536881

Please note to be eligible for this study you must have:

- have been diagnosed with Sickle Cell,
- have problems with using digital apps (eg understanding how to use them or internet access) and
- live in the UK, preferably the North of England.

SHAPE

Sickle Cell Health Awareness Perspectives & Experiences Survey

Did you see the findings from the Shape Survey, a multinational survey aimed at better understanding the experiences and unmet needs of people living with, caring for and treating individuals with Sickle Cell Disease to provide a comprehensive picture of its impact?

The new global research from Global Blood Therapeutics (GBT), aims to highlight the 'unmet needs' of sickle cell disease patients, as researchers say international healthcare systems continue to fail people from minority ethnic backgrounds.

You can find the survey https://www.gbt.com/shape/

Anusjka Regis

This issue, we speak to Anusjka Regis – one of the first people with sickle cell disorder to have a stem cell transplant.

Anusjka was diagnosed with sickle cell disorder at just a few months old. Living in Trinidad, Anusjka had a life full of pain and lots of hospital visits. Unable to take part in swimming and sports – like much of her friends and family – her life was very limited.

At the age for 20, Anusjka moved to the UK where she studied to be a nurse before having her first child in 2006. The pregnancy brought on a crisis, which resulted in her first child being born prematurely and both nearly dying.

The pain of sickle cell and effect of the disorder impacted her hips, which meant she was unable to stand for long periods. As a result, she had to stop her career in nursing.

As a sickle cell campaigner raising awareness of health inequalities, Anusjka was proactive in learning about new treatments. She discovered that stem cell treatment was being used to treat a range of conditions, but not yet sickle cell disorder. Anusjka contacted the BBC who featured the use of stem cell treatment in different conditions but not sickle cell – and because of her campaigning the NHS approved stem cell treatment for sickle cell disorder.

In April 2022 Anusjka was one of the first people with sickle cell disorder to have a stem cell transplant. Her sister, who was a suitable donor, flew to the UK from Trinidad to give Anusjka her stem cells. The treatment meant that Anusjka was in hospital for 7 weeks in complete isolation. It will take Anusjka a year to recover. Speaking to her 4 months into the transplant she is sickle cell free and is 'feeling amazing."

Anusjka says; "I am no longer worried about my future. I have no pain and I will be able to return to career I loved without any fear of having to take time off due to sickle cell disorder."

"Greater awareness is needed to others who suffer from sickle cell disorder can get the correct treatment. There are many different treatments available, and people no longer have to live in pain and suffering."

FUNDRAISING SPOTLIGHT

Elizabeth-Anionwu

kit

Joseph

Matthew Neal

Matthew Neal

Matthew Neal

Kit and Duncan

Lord Mayor of Leicester

In early July, our wonderful Patron, **Dame Elizabeth Anionwu** celebrated her 75th Birthday by raising £1,369 through her Facebook Birthday Fundraiser! Massive thank you to Dame Elizabeth for being such committed Patron and supporter of our organisation.

In early September, the **Lord Mayor of Leicester** kindly invited the SCS to take part in the High Sheriff of Nottingham and Leicestershire County Cricket Club Connecting Communities Festival. As his chosen Charity for his year in office, we are deeply honoured by his support. It was a great to attend the event and forge new relationships that would enable us to increase the reach of our work. Image shows the Lord Mayor, his niece, the **Lady Mayoress** and SCS staff.

In early September, **Kevin** walking 100km as part of the Thames Path Challenge and raised over £1200. 100km! £1200!! These are all huge numbers, and we are proud of Kevin for undertaking this challenge for SCS – he deserves a big round of applause.

Patricia, in Northampton, held her 'Autumn Fundraising Charity Ball' on 24th September to raise money for The Sickle Cell Society, which even saw an appearance from our CEO **John James**. And raise money she did! The total stands at over £1000 and it keeps rising. Well done Patricia.

Matthew Neal – former Communications Officer at SCS – took part in the Thames Bridge Trek in late September and managed to raise £360 in the process. Well done Matthew!!

Joseph attempted the Tough Mudder 2022 Challenge in late September and raised over £400. Wow! Big thanks to Joseph.

Kit and Duncan have been training for the momentous experience of riding 450km from Vietnam through to Cambodia in November. This is an amazing fundraising challenge they are undertaking for the Sickle Cell Society. Everyone at SCS is honoured and humbled by their effort.

https://www.justgiving.com/fundraising/kitnduncan

Photos: Leicester City Council

OUR MENTORING PROGRAMME

The Sickle Cell Society is re-launching its peer mentoring programme!

IS BACK!

Following on from the success of the City & Hackney mentoring programme pilot in 2017, our programme will be relaunching in the Autumn of 2022. Due to increased demand, we are now running this programme across all East London boroughs including, Barking and Dagenham, Hackney, Havering, Newham, Redbridge, Tower Hamlets and Waltham Forest.

The East London Children & Young Person's Mentoring Scheme is an innovative social model of care developed for children and young people between the ages of 10 to 24 living with Sickle Cell within the East London area.

The new programme will be run by Lead Mentor, Addassa with the help of a team of mentors Whitney, Lola, Dunstan and Lee who all live with Sickle Cell themselves. The scheme's main objective is to support and educate young people living with Sickle Cell and promote positive changes in relation to the overall management of the condition. Peer mentoring in Sickle Cell aims to improve young people's knowledge and understanding of Sickle Cell, emotional and social wellbeing, deepen understanding of where to turn for support, encourage engagement with others with Sickle Cell and assist with transition from paediatric to adult service through peer support.

We are proud to announce the re-launch of our mentoring scheme and to continue our work in promoting awareness and understanding of Sickle Cell Disease in the UK.

Do you know someone between 10-24 who lives with Sickle Cell in East London?

See the Sickle Cell Society website for more details.

CSL889 First in Human Study

CSL889 is being developed for the treatment of pain episodes (vaso-occlusive crisis; VOC) experienced by patients with SCD. In patients with SCD, heme, a molecule that is released by red blood cells, is thought to be important in the development of a pain episode. Hemopexin is a protein that is produced naturally in the body, which normally mops up excess heme. In patients with SCD, levels of hemopexin are decreased. CSL889 is a plasma-derived hemopexin that aims to correct this deficiency of hemopexin, thereby improving the symptoms of a pain episode.

A Phase 1, first in human clinical study of CSL889 is now enrolling patients who have Sickle Cell Disease (SCD) that is currently stable.

Eligible participants may receive a single administration of the study drug. The study will run for approximately 54 days involving 9 outpatient visits and a 1-night residential stay.

Further information is published on the Sickle Cell Disease Website, https://www.sicklecellsociety.org/csl889-clinical-trial/ and can also be found on ClinicalTrials.gov Phase 1, Multi-Center, Open Label, Single Ascending Dose Study to Evaluate the Safety, Tolerability, and Pharmacokinetics of CSL889 in Adult Patients With Stable Sickle Cell Disease.

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.

HELP 'GIVE BLOOD, SPREAD LOVE' STRIKE A BALANCE

If you're male, live with sickle cell, OR are a regular blood donor, then Give Blood, Spread Love want to hear from you

Give Blood, Spread Love (GBSL) is the Sickle Cell Society's blood donation project. Over the past few years, we have shared our messages about the urgent need for Black and mixed-race blood donors with thousands of people and recruited almost 1000 new members to the blood donation register.

GBSL now needs you to help us strike a gender balance among our fabulous volunteer team, the Give Blood Squad. We want to balance out the numbers of men who engage with our work (currently about 35%, compared to 65% female) to a more equal number, and we need more men to take part in our outreach and campaigns to achieve this. Could you be one of them?

As a Give Blood Squad member, we ask you to share your lived experience of sickle cell, of receiving blood transfusions, or of donating blood with our target audiences. This could involve speaking at our face-to-face events with faith groups and businesses, presenting at our online presentations with charities and community groups, or featuring in our digital campaigns. Through these activities, we aim to:

- Provide a personal perspective on a condition that many people still know too little about
- Highlight the challenges (but also the triumphs) of living with sickle cell
- Alleviate the fears and concerns people have about giving blood and what happens at a blood donation appointment
- Demonstrate the life enhancing, and lifesaving impact of blood donation, and
- Motivate people to start donating blood.

We know that men are traditionally underrepresented in many volunteering roles, especially activities that are seen to be 'helping' or 'supporting' others. Research by the Young Foundation (2012) identified a range of barriers that can stop men from coming forward as volunteers, and, crucially, noted how a visible lack of male volunteers can inhibit men from getting involved as service users or supporters. We need more male volunteers to role model methods of involvement to other men and encourage them to engage with our work, sign up to give blood, and even join us as volunteers themselves.

Dunstan Nicol-Wilson has volunteered with GBSL for over three years, sharing his experiences of living with sickle cell, and helping to challenge the stereotypes that can stop some men talking about their emotions or about personal challenges. Dunstan says, "It's so important that we hear directly from men with sickle cell as our experiences (amongst our friends, or when receiving care, for example...) can be really different to that of women. Sickle cell is equally likely to affect males as females, but we make up only a small percentage of those speaking publicly about it. We need to hear more male perspectives to encourage more men to take notice of our work and join GBSL's campaigns to increase the amount of people regularly donating blood."

Emmanuel Nola, a regular blood donor, is a newer volunteer with GBSL, and a key member of our Gym Team who hold awareness raising and donor recruitment sessions in gyms, largely targeting young, Black and mixed-race men to become donors. "There's definitely a benefit in having a man talk to other men about blood donation, about what's involved and why they should care about it; it helps to build a rapport. Also, the fact that I can speak from personal experience of being a donor myself gives weight to the conversations I have and helps reassure people that I am not asking them to do something that I haven't done myself."

Both Dunstan and Emmanuel agree that volunteering with GBSL has come with many benefits, including providing them with real opportunities to positively impact on the lives of people living with sickle cell.

If you're interested in joining Dunstan, Emmanuel, and the rest of our Give Blood Squad, please get in touch with us. You'll be asked to complete a straightforward volunteer recruitment process, and, if successful, be provided with ongoing support and training and be able to take part in a range of flexible volunteering activities.

As well as men with sickle cell, and active male blood donors, we'd also love to hear from fathers or carers of children with sickle cell who'd like to share their experiences.

Contact: Give Blood, Spread Love Project Manager – Tracy Williams tracy.williams@sicklecellsociety.org

Message us via Instagram: @givebloodspreadlove

Dunstan

New GBSL blood donor DJ

Emmanual

Children's Holiday

From Friday 5th August to Sunday 7th August, families from across the UK who all have one or more children with Sickle Cell came together online for the Sickle Cell Society Children's Holiday – a unique weekend of education, conversation, friendship and fun!

45 families enjoyed a wide variety of exciting activities including indoor gardening, zen doodling, singing, juggling, storytelling and even a virtual adventure race! They also had the opportunity to attend a learning session delivered by medical volunteers about Sickle Cell, have a Q&A with grownups who have Sickle Cell, a session focused on nutrition and also workshops around confidence and positive mental health. Every family received an activity box bursting full of arts and crafts materials, education resources and kind knitted donations from Knit For Peace. There were special activities for parents and siblings too.

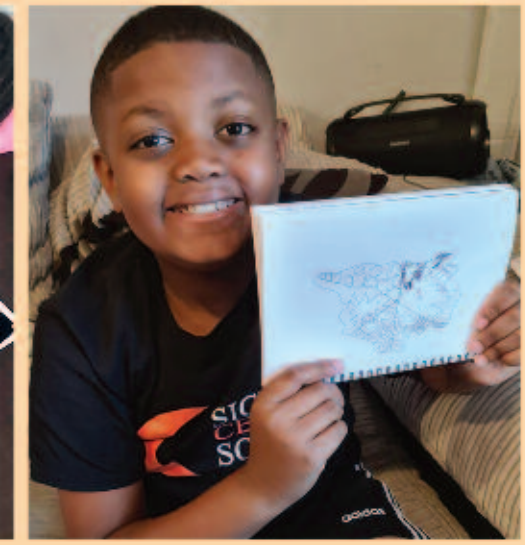
Families who attended the weekend told us:

"Thank you all so much for allowing my family to be part of a community. A community that I can relate to and grow from. A community that lets me know that me and my family are not alone. A community that is doing their very best to improve the quality of life that children with sickle and their family experience. Keep up the great and important work because it is totally needed." – Parent

"These holiday clubs make having

sickle cell less of an issue and more of a superpower. The virtual holidays are run at the pace of the children and allow siblings to find out more about how to help manage sickle cell at home and what to look for in a crisis. It also allows parents to meet likeminded individuals who share in the same day to day existence. It is such a joy and pleasure to be able to take part in the virtual holiday. I have learnt so much – not only things to look out for but ways in which to help manage sickle cell as my child grows up." – **Parent**

We are already looking forward to our Children's Holiday in 2023! If you are interested in finding out more about children's activities at the Sickle Cell Society please contact Activities Leader Taja Morgan - taja.morgan@sicklecellsociety.org



Birthday 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/

ALIYA GLADYING
shares with us her experience of living with sickle cell

As we all know sleep is very important as it is a natural healing remedy, but Sickle cell can affect how we sleep and when we sleep.

Over the years my sleep has become increasingly "bad".

When I was constantly in hospital my sleep cycle was ruined as I would go to A&E early hours to avoid the crowd.

As my health declined and I was no longer working or studying I began to have insomnia.

Trying to fall asleep when you're in crisis or usual daily pain is extremely difficult. It's just too difficult to switch off from the pain and shut your mind off.

It seems like every time I lay down is when my mind gets going even more and it's like I just can't stop thinking or shut it off. There are times when it can be intense and I feel overwhelmed.

There have been periods of time when I've only been able to get roughly 4 hours sleep a night at best for weeks at a time. Sleep is extremely important to me personally because my body is going through so much on a daily basis and the only time I'm not in pain is when I'm asleep.

I often wake up not feeling refreshed or feeling like I've had a good rest. Once I'm awake that's it for me, I can't fall asleep or take naps until I'm going to bed. I can become extremely irritable when I'm in crisis and not getting much sleep.

Not being able to sleep becomes extremely draining especially when you're battling pain.

Thanks to Aliya for sharing her experiences with us.

ANTHONY NOLAN

The Sickle Cell Society are pleased to have worked with Anthony Nolan on their Sickle Cell & Stem Cell Transplant webpage, providing insight and feedback to ensure clearer information for people with Sickle Cell. This is now live on the Anthony Nolan Website: https://bit.ly/3RAqNAF

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

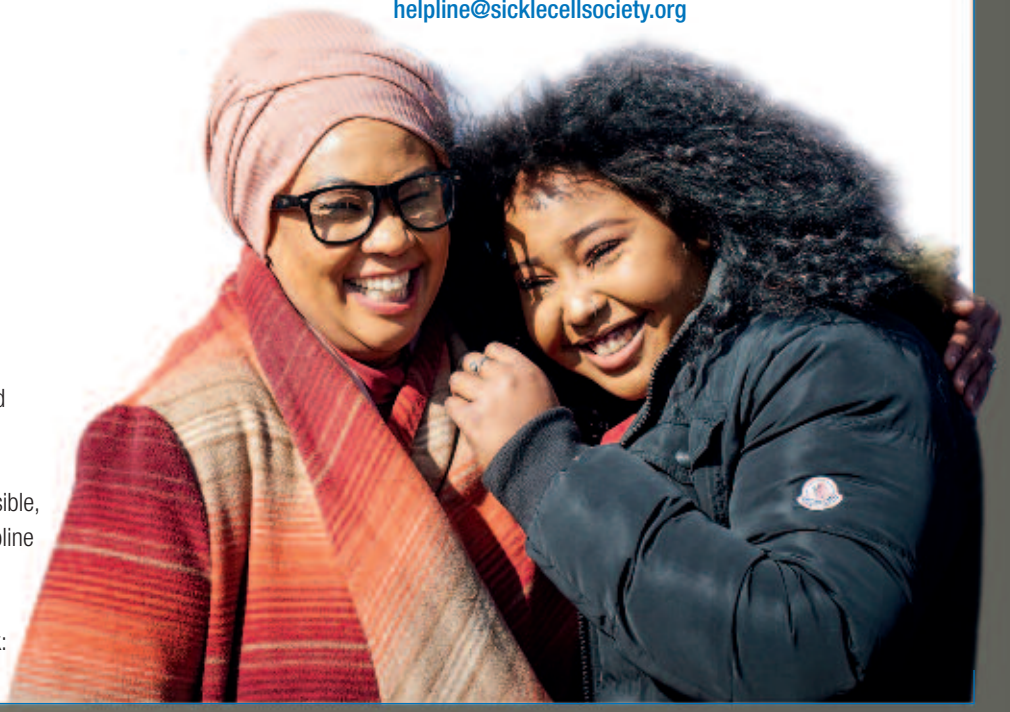
We want to support you as best as possible, that is why we have opened up our helpline to 5 days a week from 10am to 5pm. Before calling, please see the correct number to call for each day of the week:

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



Online Shopping

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

During the pandemic, online shopping has become even more important. More and more people this year will be avoiding the high-streets and shopping online.

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:
sandra.reyes-hayduk@sicklecellsociety.org

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. 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