

# sicklecell



SICKLE  
CELL  
SOCIETY

THE NEWSLETTER OF THE SICKLE CELL SOCIETY

SPRING 2021



**In this issue:**

**Our COVID-19 report  
Launch of a new digital exhibition  
A Screening Programme special  
Plus, so much more...**  
[www.sicklecellsociety.org](http://www.sicklecellsociety.org)

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## COVER

A few of our virtual events and meetings held this year

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## Introduction

I hope you and your loved ones are safe and well and continue to stay so.

The last six months have continued to be dominated by COVID-19 but that hasn't slowed down our work, from the start of the first lockdown almost a year ago. We have been kept very busy, adapting much of our work to be accessed online, as well as making sure that the latest information and guidance is available for everyone in the sickle cell community. Our usual work has also continued, and we have lots of exciting projects to talk about in this newsletter.

With COVID-19 taking up a large part of our lives, and with sickle cell falling into the clinically extremely vulnerable section, we have been working hard to provide support, information and guidance for the sickle cell community.

Our staff team, trustees and volunteers have had to adapt at pace, be resilient and plan ahead to manage the financial challenges imposed by COVID-19. This has not been easy. I want to take this opportunity to thank our leadership team, staff and volunteers for their support in dealing with these unprecedented challenges.

You may remember that back in May, June and September, we ran Live Q&As with healthcare professionals to answer your questions around sickle cell and COVID-19. With the approved vaccines being offered, we wanted to do a similar series, so in January and February we produced a three-part series in order to provide information and to address any concerns you may have around the vaccine. We were delighted to be joined by Dr Anna Goodman (consultant in infectious diseases and general medicine), Dr Rachel Kesse-Adu (consultant haematologist) and Dr Abbie Wickham (clinical psychologist) for these

videos, as well as sickle cell patients sharing their experiences.

Patient experience has been at the heart of our COVID-19 response, and as our role of secretariat of the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG) we published a report into the impact of the COVID-19 pandemic on the sickle cell community. You can read all about this report and the results of our research, later in this newsletter.

Following up from the success of our first-ever virtual Children's Holiday, we have been running a whole range of fun virtual children's activities. The children have been enjoying everything from carnival workshops and festive performances to scavenger hunts and positive wellbeing sessions. Read on to learn more about what they have been up to.

We have also engaged in the digital space through our new digital exhibition. Over the last year, the Our Journey Our Story project has been collecting together photos, documents, stories, artwork and more to form the first sickle cell archive. We are proud to be able to launch this archive in the form of a digital exhibition.

"Our Journey, Our Story: History and Memory of Sickle Cell Anaemia in Britain 1950 – 2020" was launched on the Black Cultural Archive website, and is an exploratory exhibition on the history of sickle cell, the NHS and the Black British community. The digital exhibition is a celebration of the progress made over the last 70 years and to recognise those who have worked to make this progress possible.

Although a digital exhibition was not what we had initially planned, we are excited that the exhibition will be able to be enjoyed

across the UK and the world by those who may not have been able to access it otherwise. Get a taste of this first-of-its-kind exhibition later in this newsletter.

In this edition of the newsletter we also have a special feature on the NHS Screening Programme. The NHS Screening programme is one of our largest projects, a collaboration between us, NHS England, Public Health England and the UK Thalassaemia Society, and looks to provide the patient voice on all matters related to screening.

In a special interview with our NHS Engagement Lead, Iyamide Thomas, you can find out more about the day-to-day work of the screening programme as well as three new publications which have recently been launched.

Blood donation continues to be a high priority for the sickle cell community. Our South London Gives and Give Love Spread Love projects have both been working hard to recruit more black heritage blood donors. The projects have been

working with celebrity influencers, community groups and organisations, local and national media, 'squad members' and social media to spread the word far and wide and have already recruited 633 new blood donors. Read more about their achievements and how you can get involved later on.

Finally, we catch up with Basil in a new service user article. You may remember Basil from his brilliant article in our Spring 2020 newsletter. He is back with a new article, sharing his experience of living with sickle cell throughout the lockdown.

With the vaccine being more broadly distributed, hope is on the horizon. There is still a long way to go, but we will continue to work hard to support the sickle cell community along the way. We hope you enjoy this newsletter, and thank you for all of your support.

**John James OBE** Chief Executive and  
**Michele Salter** Vice-Chair & Treasurer

*John James OBE*

*Michele Salter*



# Cast Aside and Fo

The All-Party Parliamentary Group for Sickle Cell and Thalassaemia publishes a new report into the impact of the COVID-19 pandemic on the sickle cell community.

Cast Aside and Forgotten is the latest report from the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG). Taking its name from a quote by a person living with sickle cell in the midlands, the report investigates the experiences of those living with sickle cell or caring for someone with sickle cell during the COVID-19 pandemic

The pandemic had an unsteady start for those with sickle cell disease (an inherited blood condition which predominantly affects people from African and Caribbean backgrounds) when the NHS's people at high risk (clinically extremely vulnerable) list included Homozygous sickle cell disease but failed to include other genotypes of sickle cell disease. After this oversight was rectified, it was then discovered through countless anecdotal accounts that those with sickle cell trait were being told erroneously they were also being classed as clinically extremely vulnerable. These two incidents failed to reassure the sickle cell community, and hence the Sickle Cell



Rt Hon Pat McFadden MP (Chair of the SCTAPPG)

Society (SCS) knew it was crucial that more must be done by those outside central government to safeguard those living with sickle cell disease.

The SCS looked to stem this outpouring of anxiety by providing expert advice and support through the plethora of services it offers, whether that's through its helpline which was inundated with queries, or its website

providing the most up-to-date guidance.

The SCTAPPG then worked with the SCS to commission a survey into the ramifications that coronavirus would have on the sickle cell community and their primary caregivers. The survey was launched on 28th of May 2020 and disseminated through the SCS membership, as well as through patient groups and clinical networks.

Amongst a host of objectives, the survey aimed to collect data to determine whether those living with sickle cell or caring for someone with sickle cell disease are receiving all the information required, and whether the government guidance is suitable for their circumstance.

The report aims to highlight the prevailing issues that are affecting the sickle cell community during this pandemic as well as, in respondents' own words, offering an insight into the reality of living day-to-day during the government lockdown.

It also seeks to examine this COVID-19 pandemic through the lens of the structural injustices that exist which have only served to exacerbate the plight of people living with sickle cell disease. The key findings have aided the SCTAPPG to be in a position to make a host of substantive policy recommendations in order to ensure the safety of this clinically vulnerable cohort going forward.

"This report paints a picture of the experience of the pandemic through the eyes of those living with sickle cell. As in other walks of life is shows the need for more understanding of this condition as well as the need for better treatment. I hope the report is read by those who can make a difference in health care, the benefits system and many other walks of life" – Rt Hon Pat McFadden MP (Chair of the SCTAPPG)

## Key Survey Findings

50.5% of respondents informed us that the COVID-19 had affected their access to healthcare services in their locality. It is a chilling statistic that just over half of all respondents revealed that their usual health pathways were being disrupted by the pandemic.



A visual representation of the qualitative evidence given on the subject of mental health reveals a very despondent and dejected cohort

# Forgotten – A Report



One respondent explained that “outpatient appointments have moved to phone calls, GP appointments cancelled, I have not been able to go to chemists due to shielding, so I had to manage pain for a month while waiting for my next check-up.”

Another said that it was “harder to get prescriptions and also getting medication delivered on time to manage my sickle cell. I have not been able to have regular blood tests to help monitor my condition.”

This failure to access healthcare services will most likely be in direct contradiction of doctors’ orders – who are best placed administer the most effective treatments and provide advice on healthcare needs. There was a general consensus that cancellation of GP service provision/outpatient appointments/annual consultations/ planned surgeries/ planned routine check-up’s/scans is a prevailing issue.

Respondents had an overwhelming sense of fear and trepidation about the future, and how these delays and missed appointments will

have itself brought on a crisis (episodes of severe pain caused when sickle cells stick together, causing blockages in the small blood vessels).

Furthermore, the nature of having to conduct appointments over the phone has resulted in cases whereby service users have felt an inability to be able communicate effectively one’s condition. One person said their “GP refused face to face appointment so I ended up in hospital with severe pneumonia because they didn’t inspect my chest.”

This has people feeling helpless to improve and manage their condition. What’s more, a reliance on support networks to carry out visits to the chemists/pharmacies puts those without those very networks at

affect their health outcomes.

One person said: “I’m not sure how I’m going to get a new prescription for Hydroxyurea or any of my other medication. And those not fortunate enough to have support networks having to take the biggest risk of them all and fend for themselves.”

From renal to haematologist appointments, it is apparent there is distress and panic that services users are not being afforded the opportunity to effectively manage their condition by using the host of services they require. The cohort feels a sense of neglect with people lamenting that they have not had a blood test for months. Of those who hadn’t been able to access all their healthcare services, 20.5% of that cohort had reported this

risk of failing to adhere to medical advice through no fault of their own.

## Conclusion

Intrinsically COVID-19 does not discriminate, pandemics don’t choose their victims and a virus does not select its host. But what is safe to say is that in a society where structural inequalities exist whether that be by socio-economic background, race, gender, disability – COVID-19 does discriminate.

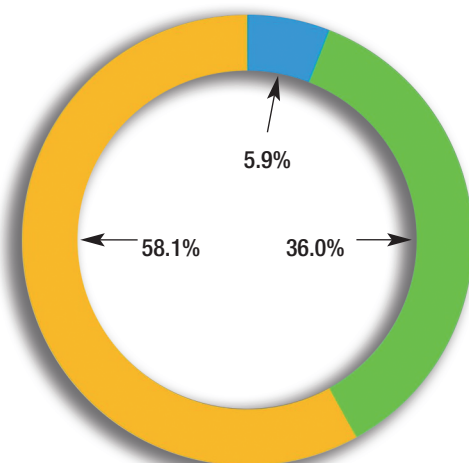
The likelihood of contracting the virus increases or decreases dependent on these aforementioned variables. And though it has not been proved beyond doubt that having sickle cell decreases your chance of survival, your race and socio-economic background have been proven to increase your likelihood of contracting the virus. If you take one of our members who is BAME, has sickle cell and from a lower socio-economic background, they are more likely to suffer from COVID-19.

Consequently, COVID-19 does discriminate, it has served to exacerbate and amplify the health inequalities that already exist.

Download the full report at our website: <https://www.sicklecellsociety.org/cast-aside-and-forgotten/>

**Chart 6 – To what extent, if at all, are you worried about being more at risk of the consequences of COVID-19 because of your sickle cell?**

● Not worried ● Worried ● Very worried



# 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/](http://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/](http://www.sicklecellsociety.org/birthdayfundraisers/)



## Child

The children have been taking part in several Children Activities over the last few months including a Virtual Carnival Themed Workshop which took place on Saturday 26th September; there were arts and crafts and a dance session led by Nzinga Dance.

For Black History Month we had a few different activities such as an Online Scavenger Hunt, a Storytelling Workshop by Usifu Jalloh and a workshop about the history of sickle cell by Alinta and Laurel. "Keep up the good work. Thanks to Taj & all





# ren Activities

the children for the good work” – Parent

Over the Christmas period the children met online over a few weeks to create their own Virtual Festive Performance performed for family and friends on Saturday 19th December. To kick off the year, we had Wellbeing Workshops lead an online workshop about Positive Wellbeing and how to stay positive especially during these times on Saturday 16th January 2021. We have more workshops taking place throughout the rest of the year, if you would like to join please check out our website for more information.

“Taking part in the festive performance made me feel very excited and less isolated as a sickle cell patient and during lockdown” – Child with sickle cell



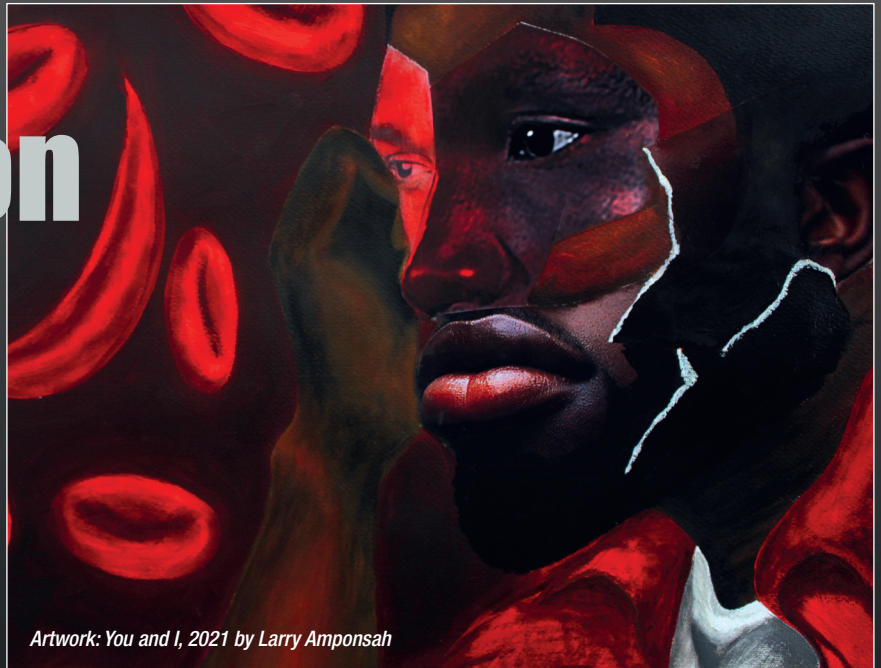
# Digital Exhibition Launch

The Sickle Cell Society launch digital exhibition on the history of sickle cell in the UK at Black Cultural Archives. The Sickle Cell Society launches 2021 with an exploratory exhibition on the history of sickle cell, the NHS and the Black British community with Black Cultural Archives (BCA).

Our Journey, Our Story: History and Memory of Sickle Cell Anaemia in Britain 1950 – 2020 (launched on the BCA website on Monday 25th January) unveils the campaign to make sure that sickle cell was recognised by medical professionals and how treatment has evolved.

For the first time, the exhibition collects the testimonies and experiences of people living with sickle cell; photographs and archives about the history of sickle cell campaigning; and original art by Black artists.

Sickle cell affects approximately 15,000 people in the UK. People with sickle cell can experience pain, strokes, fatigue and many other symptoms, and it can be life-threatening. Sickle cell was

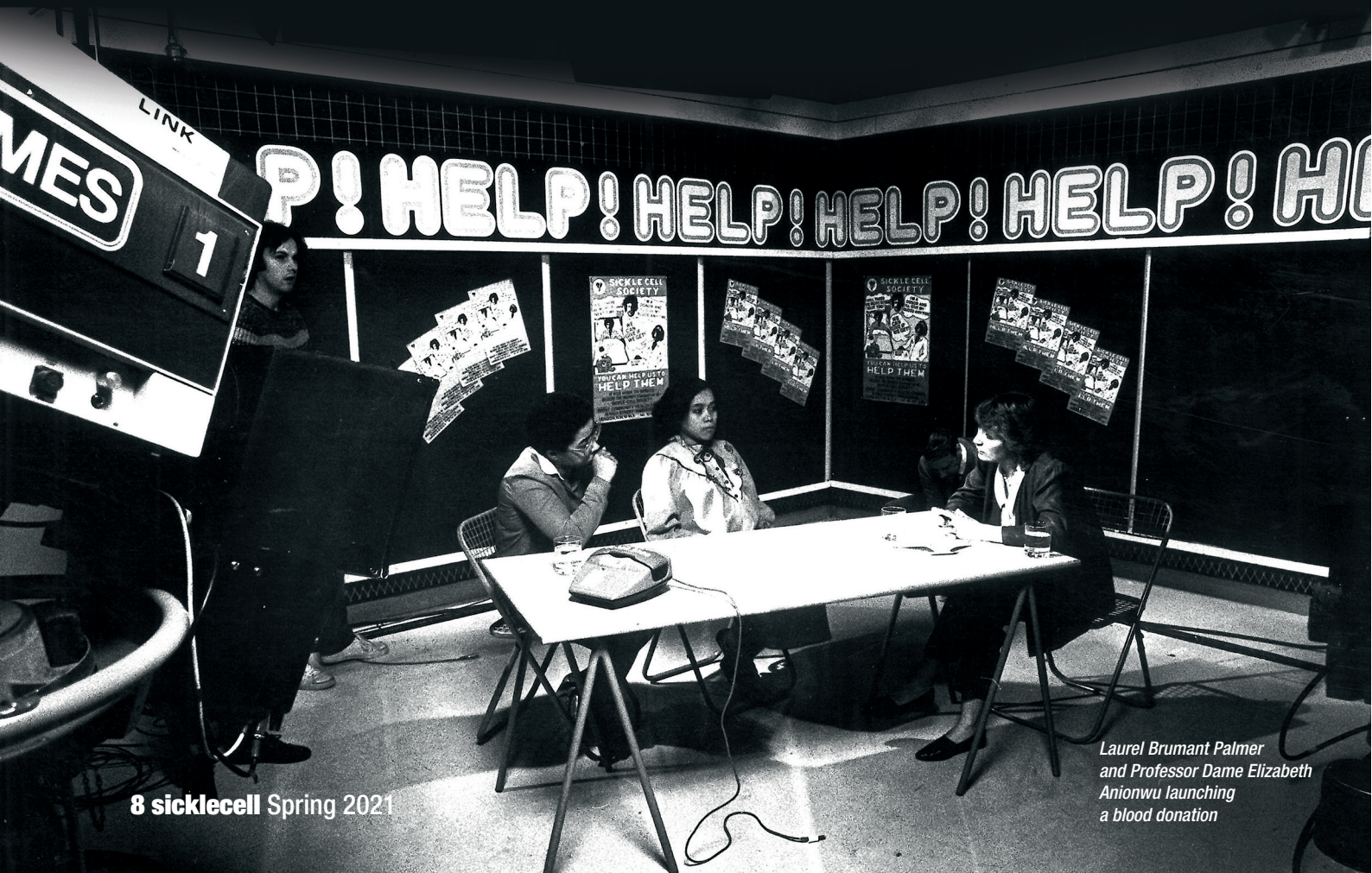


Artwork: *You and I, 2021* by Larry Amponsah

misunderstood by doctors and underfunded for decades.

Against the backdrop of British Black Power, the first black MPs in Parliament, and anti-racist campaigning; patients, families, nurses and doctors campaigned for equitable treatment in the NHS, and better awareness of the condition. As an illness that was an object of fascination for geneticists and anthropologists as a marker of 'race', this exhibition seeks to turn that on its head and present the condition as it is seen, understood and managed by the people affected by it.

Our Journey, Our Story: History and Memory of Sickle Cell Anaemia in Britain 1950 – 2020 is available online at: [www.bcaexhibits.org/exhibits/our-journey/](http://www.bcaexhibits.org/exhibits/our-journey/)





# 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 the last 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/](http://www.sicklecellsociety.org/leaving-a-gift/)

or by calling our

**Fundraising Officer on 020 8963 7793**

Thank you, we greatly appreciate your support.



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

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

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

## Why become a member?

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

# Become a Member

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

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

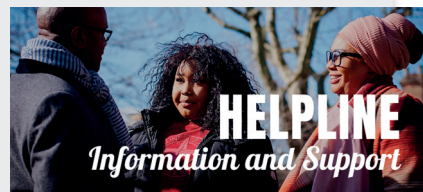


# Helpline

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



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.

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/](http://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](mailto: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.**

# 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/](http://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: [ainhoa.munoz@sicklecellsociety.org](mailto:ainhoa.munoz@sicklecellsociety.org)

# South London Gives



*Brenda Smith*

Over the past 2 years, South London Gives (SLG) has engaged with individuals and communities to explain the vital link between increasing the amount of black-heritage people giving blood and ensuring those with sickle cell have access to the ethnically matched blood they need. South London Gives is now at the end of this period of funding, which was provided by NHSBT, and is exploring ways we can continue this work.

During this time we have highlighted the life changing difference blood donation makes, enabling those most severely affected by sickle cell to stay alive and well. We have had difficult conversations about the barriers that stop some potential donors coming forward and explained the facts and figures of black-heritage blood donation. We have been privileged to involve a team of committed and skilled volunteers, many of whom are affected by sickle cell and all of whom have gone the extra mile to support this essential work. Due to Covid, we adapted our approach, continued to spread our message online, across England, and introduced and collaborated with our new, digitally focused project, Give Blood, Spread Love.

There is still much to do; more people with sickle cell

are being offered treatments requiring donated blood and numbers of new black-heritage blood donors still need to rise. The ongoing Covid 19 pandemic has presented further challenges in terms of encouraging new donors to step forward, however, we continue to support people to sign up to save a life [bit.ly/scsgiveblood](https://bit.ly/scsgiveblood) and to donate blood as an individual, and alongside their friends, family and colleagues throughout this time.

Below is a sample of SLG's and Give Blood, Spread Love's blood donation achievements so far. We will share SLG's project evaluation findings in the next Society newsletter and update you on how we will take this work forward.

- ✓ 5000+ people reached at face to face events at organisations, churches, businesses and community groups
- ✓ Development of a new volunteer recruitment and training programme, securing involvement from skilled professionals in the sickle cell community
- ✓ Recruitment and training of 30 Community Advocates
- ✓ Presentations and workshops delivered to 125 agencies
- ✓ Joint media projects with BBC TV, BBC Works, Terumo, Premier Radio, Supreme Radio
- ✓ 35 Give Blood, Spread Love 'squad members' spreading awareness around blood donation.
- ✓ Over 1000 engaged social media followers
- ✓ Our social media posts have appeared over 50,000 times
- ✓ Developed and shared a suite of digital blood donation resources with over 30 organisations and individuals
- ✓ Over 19,000 unique users have seen our content
- ✓ Frequent celebrity & influencer endorsements; Yinka Bokinni, Nush Cope & Penny Belle
- ✓ Launched a group blood donation support service
- ✓ Recruited 650 new blood donors

# Waitrose and John Lewis Donation

Over Black History Month last year, John Lewis and Waitrose raised a massive £20,766 to support our work. Our Chief Executive, John James OBE, went along to their flagship Oxford Street store to pick up the check and see their Black History Month Exhibition.

We also spoke to Senior Store Manager, Marc Valace, about why they chose to support sickle cell, and why they feel Black History Month and charity giving are important for businesses to support.

## Interview with Marc Valace SENIOR STORE MANAGER

### Tell us a little about yourself and the work you do?

I am a Senior Store Manager at Waitrose Clapham Common. Leading a team of 60 Partners in a densely traded 3,000sq foot shop. We trade traditionally through walk in and through Deliveroo, which we lead the business in on order numbers. My goal is to create and deliver a clear vision to satisfy both our customers and Partners. Outside of my shop remit I am a lead in diversity for ethnic minority Partners and flexible working.

### Why did you choose to raise money for sickle cell?

My wife's father is a sufferer and advocate for

sickle cell. I knew little about the disease before I met him but have since experienced its effect through him. My wife and children are also carriers through trait. With the killing of George Floyd in the USA, I made it a personal mission to raise awareness of Black Partners and their experiences in the Partnership, as part of this I influenced London shops to come together and donate as one to 3 Charities that impact Black lives in the capital. Sickle cell was first on the list!

### Tell us a little bit about your Black History Month exhibition?

Our exhibition was to raise awareness of our culture in a relaxing environment. Both giving Partners the freedom within the framework and natural engagement to deliver experience and education. This was a first for our business and all research and delivery was funded by the business. We welcomed over 300 guests, who



John James OBE at the Black History Month Exhibition

were all blown away by the authenticity and engagement. A true celebration of past and present.

### Why do you think it is important for corporations to get involved with Black History Month, and charity giving?

Without people there is no business or corporations. Spending the time and effort to educate, remember and celebrate all cultural celebrations is key to getting to know your employees and raising morale. Understanding your workforce can help you choose charities that impact their lives or lives of loved ones. Adding a sense of belonging, in which the corporation gets back in return through increased pride and profitability. Forming bonds and leaving footprints with charities is important to raise their awareness and support the cause.

### What do you think we can do to raise more awareness of sickle cell?

Reach out to businesses to educate them on what the disease is and how many people it affects. Propose to run an education session. Maybe try to engage directly with D&I leads within the organisation. Don't be afraid to call out what we have done together as JL is very respected, think of how you would like to build on our relationship to leverage your reputation.



John James OBE receiving the check for the Sickle Cell Society from John Lewis and Waitrose

# FUNDRAISING SPOTLIGHT



A massive thank you to 11-year old Cayden Debrah who raised £1,738 during the Christmas school holidays by running a marathon (26.4 miles) in 12 days.



A big thank you to Robert Anderton who raised £650 by dying his hair red.

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 Rosemarie Clarke who raised £727 with a Dry January challenge.

A big thank you to Lucy Talbot who raised £245 in loving memory of Lincoln Talbot.

A big thank you to James who raised £17 with a Sickle Cell at Home fundraiser.

A huge thank you to Paula and Rebecca for raising £560 with a 150 km Christmas run in loving memory of Bobby Sasu – Twum.

A massive thank you to the Ware Ukulele Group for raising money with their digital Christmas concert.

A big thank you to Madeha Zaman, Abisola Akande, Gabriel Pineda, Mohammed Yusuf Omar, Simeon Sevilla and Sukurat Makinde for raising £262 with their National Citizen Service fundraiser.

A massive thank you to Emma Duke and Gallagher's Risk and Compliance Team for raising £1,610 with their step challenge fundraiser.

A big thank you to Charity at Chubb for raising £260 during their October Giving Day.

A big thank you to Grace Mansah-Owusu who raised £720 over Sickle Cell Awareness Month & Black History Month.

A big thank you to Lloyds Banking Group for raising £65 for Black History Month.

A massive thank you to Black Twitch UK who raised £1,051 with a unique video game fundraiser.

A big thank you to Paula Powell for raising £30 with a Sickle Cell at Home fundraiser.



A huge thank you to Danny Christie for raising £270 with his Red Walk for Sickle Cell.



A massive thank you to Mark Alexander who raised £730 with a New Year's Eve Charity Zoom Party.

A huge thank you to Selina Odiaka and the DLL UK Diversity and Inclusion – Black History Month Team for raising £655.

A massive thank you to Sarah Oloko for raising £500 over Black History Month.

A big thank you to Daniela Adoasi and EMEA DIB who raised £440 for Black History Month.

A huge thank you to UCL ACS who raised £278 for their charity week.

A big thank you to SnapNoir on Snapchat who raised £1,000 for Black History Month.

A massive thank you to Adeyemi Michael, who donated his honorarium of £1,500 for being a guest speaker on a panel discussion hosted by Netflix together with their Talent team.

A big thank you to Moma's Cookies who raised £43.50 with their second advocate campaign with us.

Thank you to all of our Facebook Fundraisers for raising money for us, with a special thank you to Kate Ogah, Sheree Hall and Ojeaga Ojehomon who were our top fundraisers.



# Life as an NHS Engagement Lead

Many moons ago, the Sickle Cell Society (SCS) newsletter would dedicate pages to an interview with someone from the sickle cell community, such as a health professional, voluntary worker or sickle cell service user. Last October, I did a comprehensive interview for the UK Thalassaemia Society (UKTS) special magazine on screening since I work jointly with them on a project commissioned by the NHS Sickle Cell and Thalassaemia (NHS SCT) Screening Programme. Therefore with these two things in mind, I decided this newsletter report on the screening project will be a revised and updated version of the UKTS interview I did, also giving readers the opportunity to learn a bit more about me!

## What is your past professional and work experience and how has this helped with your work at the Sickle Cell Society?

I grew up with a dad who was a medical doctor who hoped I would follow in his footsteps. However, dissecting a rat at 'A' Level biology sealed the fact I was too squeamish for medicine, so I opted to read Chemistry degrees at University instead! That said, most of my work experience gravitated towards health. I first worked in the mid 80's as **Research Development Officer** at the Sickle Cell Anaemia Research Foundation, a voluntary organisation in Hammersmith, then in 1988 at Newham Health Promotion as a **Health Education Officer** mainly to raise awareness of sickle cell amongst their Black, Asian and Minority Ethnic (BAME) community. Interestingly that's how far back I have known now retired sickle cell nurse counsellor Comfort Okolo! In 1991, I joined the Cancer Screening Evaluation Unit at the Institute of Cancer Research (ICR) as the **Trial Co-ordinator** of a National Breast Cancer Screening Trial investigating the effect of annual breast screening of women starting at ages 40 -41. That job took me all over the UK. I was thrilled to join the Society in October 2004 when my contract at the ICR finally ended. I joined as the Society's South London **Regional Care Advisor**. So, I actually had past experience of both sickle cell and screening before coming to the Society!

## Do you have any personal experience of Sickle Cell Disease?

The only personal experience of sickle cell I have is knowing that my haemoglobin genotype



*Iyamide Thomas – NHS Engagement Lead*

is AA and that of my dad was AS. Growing up in Sierra Leone I had two friends with sickle cell one of which I knew had the condition. The other was someone I knew at primary school who was always absent, had extremely yellow eyes and sallow looking skin. I now know that was because he had sickle cell and often wonder what became of him after we lost touch!

## What does your job at the Sickle Cell Society involve?

I have actually had three job titles since I joined the SCS in October 2004! I first joined as one of five Regional Care Advisors and my remit was mainly casework with individuals and families affected by sickle cell living in South London. My next two roles as **NHS Outreach Project Lead** and my current role as **NHS Engagement Lead** were for projects commissioned by the NHS SCT Screening Programme. In my current role the Screening Programme wanted the SCS (as Lead organisation) and UKTS to work jointly with them to provide service user input and ensure they provide an improved and user-focussed service.

## What did your role as NHS Outreach Project Lead involve?

In 2009, the Screening Programme commissioned the SCS for a project to raise awareness of sickle cell, screening and associated myths using a DVD called 'The Family Legacy'. I was pleased about this as I had stated the performing arts was a good and engaging way to spread health messages. As NHS Outreach Project Lead I led a small team that conducted facilitated DVD film sessions at innovative places like barber and hairdresser shops, mosques, restaurants and even in family homes. That was something new for the Screening Programme and they particularly liked the fact I organised sessions in barber



*Iyamide delivers a sickle cell session at a barbershop in South London*

# – Up Close with Iyamide Thomas

shops to reach the men, who incidentally were not always there to have their hair cut! This outreach can be found on the Government website ([www.gov.uk](http://www.gov.uk)) as a learning for others wanting to do outreach with Black and Asian communities.

## What work has the SCS / UKTS collaboration with the Screening Programme done to date?

The first SCS / UKTS collaboration commenced in 2016 and the main remit was to investigate barriers affecting the timeliness of the offers of screening and Prenatal Diagnosis (PND). The Societies conducted interviews with women and couples who had recently gone through antenatal screening for sickle cell or thalassaemia and documented their experiences in a publication known as **'Parents' Stories'** which is on our website. These stories raised a number of screening issues for the public (present early in pregnancy, contact maternity and specialist counselling centres directly or your GP), for screening providers (provide direct access to Specialist Nurse Counsellors to known 'at-risk' couples). As a result of parents' feedback the Screening Programme revised its system of 'fast-tracking' couples at risk of having an affected baby, as well as revising its screening handbook. For the current commission which commenced in 2018, the SCS & UKTS have done a lot of community outreach to raise awareness of screening issues from the Parents' Stories, raise awareness of newborn care for affected babies and the National Haemoglobinopathy Registry. Myself, a representative from UKTS and one of our sickle cell service users were part of a 'Sickle Cell and Thalassaemia Counselling Skills and Knowledge Working Group' that produced **'Sickle Cell & Thalassaemia Counselling, Knowledge & Skills Guidelines'**, a publication targeted at SCT specialist nurse counsellors and other health professionals such as genetic counsellors and specialist midwives. SCS & UKTS also produced four lovely posters to raise general awareness of sickle cell, thalassaemia and screening and though dissemination of these have occurred, the pandemic has caused some hindrance!

One key aspect of this current commission was related only to sickle cell and that was for the SCS to produce new editions of two



*Iyamide, Roanna and Romaine Maharaj from UKTS run a joint awareness stall*

publications: **'Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care'** (last updated in 2010) and **'A Parent's Guide to Managing Sickle Cell Disease'** (last updated in 2012). After forming working groups made up of relevant clinicians and other health professionals to produce these publications, I also conducted face-to-face and online consultations with sickle cell service users, health professionals and other stakeholders so their feedback could be included. On 28th January 2021 all three publications were launched in an event hosted by Public Health England (see separate article on page 17).

## What are you currently working on in relation to screening?

Jointly with UKTS we are helping the Screening Programme to revise an E-learning resource that was produced around 2016 for health professionals working on the screening pathway. This will also contain new videos of ourselves and service users from each Society. The pandemic means we might have to film these using Zoom though! The SCS and UKTS are also part of a Manuscript Task and Finish Group writing and publishing a series of articles and blogs about the Sickle Cell & Thalassaemia Counselling, Knowledge & Skills Guidelines in **Nursing Times** which is a monthly magazine targeted at nurses. Another huge piece of project work the Societies are about to embark on is a consultation via various online focus

groups to determine parents' (and would-be parents) views on the communication of newborn screening results when their baby is either a carrier or affected with sickle cell or thalassaemia. We plan to do separate focus groups for men and women and it will be interesting to see what the different sexes say!

## How do you find collaborating with UKTS/ SCS and PHE?

As a result of staff changes in both UKTS and the Screening Programme since the SCS was first commissioned by the Screening Programme, I was a bit apprehensive whether the new relationships I would have to build would be as good as that with previous colleagues. However, I need not have worried as we are all working very well together on the project.

## How has the pandemic affected your work and you?

The pandemic has definitely created challenges for our work as social distancing and shielding directives have meant us having to create new ways of working virtually to engage our user group. This has its advantages and disadvantages in that as no travelling out of your home is involved we get more attendance at events and meetings. However, not everyone is familiar with Zoom or Microsoft Teams and nothing beats face-to-face meetings in my opinion! With regards to the work programme we produced something called a 'restore' ▶



*Iyamide with colleagues from the sickle cell world at Museum of London Docklands*

document outlining how we planned to mitigate against the changes brought by the pandemic and the Project Advisory Group reviews this document periodically to see how we are doing. As for me, I was used to working from home prior to the pandemic but going out only for groceries and exercise was definitely not something I was used to!

**What would you say have been the major achievements of the NHS SCT Screening Programme?**

In 2001, the NHS SCT Screening Programme was established as the world's first linked programme of antenatal and newborn screening for sickle cell. That is they screen parents-to-be before the birth of their baby and these results are then in a screening pathway linked to screening of their newborn baby. That's a major achievement to develop and implement a successful Screening Programme that is respected and used as a model for other screening programmes across the world! 2016 was the 10th anniversary of full roll-out of newborn screening and 7 million newborn babies had been screened for sickle cell and just over 3,600 diagnosed with sickle cell. Obviously 5 years down the line these numbers have now increased. Another achievement is the fact that the Screening Programme were innovative enough to partner Patient Societies (i.e. SCS and UKTS) to do outreach which has really raised awareness of sickle cell and screening among high risk populations, who as a result are able to make informed reproductive choices. When I started working with the Programme, 360 babies were born annually with sickle cell and that number now averages 280. I believe a lot of this is due to outreach and couples at risk of having an affected baby

being able to access screening, counselling, pre-natal diagnosis and good screening information which has enabled them to make informed choices.

**The NHS SCT Screening Programme currently focuses on pregnant women (and partners where necessary) but ideally do you think people should know their carrier status much earlier?**

Yes, it's good for people to know their 'carrier status' or haemoglobin genotype much before the antenatal screening stage as this enables more informed choice and for some this might even dictate how they choose their partners! Screening before pregnancy is known as '**pre-conception**' screening and we do get asked about this frequently. This is particularly relevant if you are thinking of starting a family yourself and you know of family members who carry the sickle cell gene. Such individuals should speak to their GP about being tested or go to one of the NHS Sickle Cell & Thalassaemia Screening Centres listed on our



*It's Zoom, Teams or never!*

Society website (by the way the search field is currently at the bottom of the homepage). Some churches (certainly in Africa) do pre-marital counselling to raise awareness of knowing your carrier status before marriage and some years ago I worked with a church in South London which had a 'JB4' 'Just Before Marriage' campaign, although I still think that's too late as you are at the verge of walking down the aisle by then! On 4th and 5th November 2008 the Screening Programme hosted an international residential conference in Greenwich to discuss the feasibility of developing 'pre-conception' screening in the UK. I remember the date as that was when Obama got elected and many of us hardly slept on the 4th! The Programme did come up with a preconception screening policy and I recall it had clear recommendations on how and when it is most effective to screen pre-conceptually for genetic disorders like sickle cell.

**What are your personal interests or things you like to do in your free time?**

I have always liked theatre, mostly African plays mainly staged in fringe theatre, although more recently such plays are sometimes put on at the National Theatre (NT). One very enjoyable play I saw at the NT several years ago called '**Barber Shop Chronicles**' really reminded me of the barbershop screening outreach I did with the Family Legacy. Incidentally, I went to see it with colleagues from the Screening Programme! I also like things to do with history, heritage and culture and I go to museums such as the British Museum, Horniman and Museum of London if they hold artifacts or exhibitions I am interested in. In fact my interest in my Sierra Leonean 'Krio' heritage and its important link to British history made me initiate and co-curate an exhibition called '**The Krios of Sierra Leone**' currently at the Museum of London Docklands. I also put in a bit on sickle cell in a section that discusses two 'Notable Krios': Dr Africanus Horton (who wrote about the condition as far back as 1874) and the Society's patron, actress Ellen Thomas. This has definitely raised awareness to lots of the museum's visitors who would never have heard of sickle cell before and can now go and Google it! The exhibition opened in September 2019 and luckily I was able to give a 'curator's tour' to a group of two retired haematologists, a service user, colleagues from the Screening Programme and our Sickle Cell Society Chair just two weeks before the first national lockdown in March 2020!



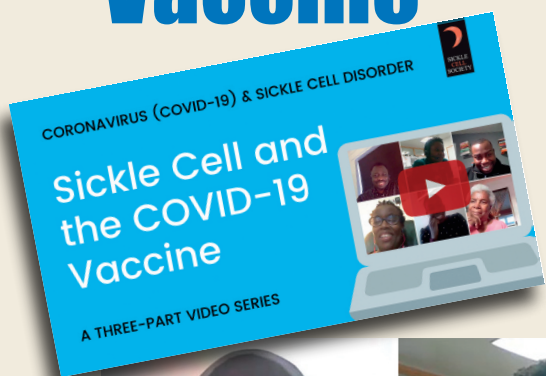


# Sickle Cell and the COVID-19 Vaccine



*Dr Anna Goodman (Consultant in Infectious Diseases and General Medicine at Guy's and St Thomas)*

With the COVID-19 vaccine being rolled out, we have been working with clinicians and sickle cell patients, to bring you a range of videos, providing everything you need to know about the COVID-19 vaccine.



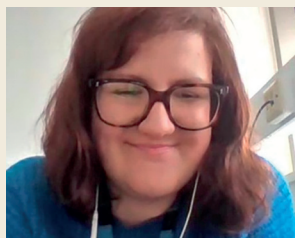
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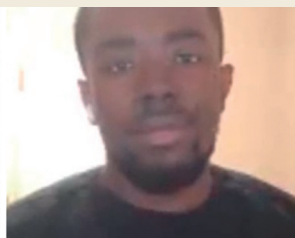
Dr Rachel Kesse-Adu



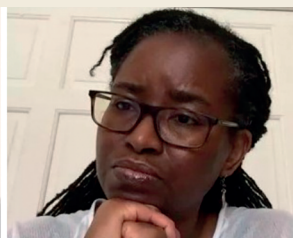
Laurel



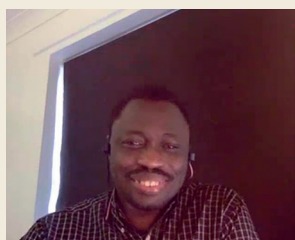
Dr Abbie Wickham



Kojo



Lynette



Ayo



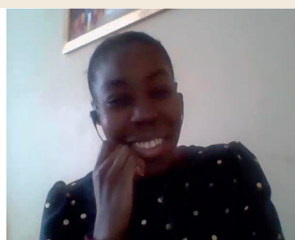
Dr Rachel Kesse-Adu



Anthony



Liz



Emma



Ansella

## Learn about the COVID-19 Vaccine

We talked with Dr Anna Goodman, Consultant in Infectious Diseases and General Medicine at Guy's and St Thomas to learn more about the COVID-19 vaccine.

## Sickle Cell, COVID-19 & Vaccination

On Wednesday 27th January 2021 we joined with clinicians and sickle cell patients from across the country to learn more about sickle cell and COVID-19 and to ask questions about the COVID-19 vaccines.

We started with a short introduction by SCS Chief Executive, John James OBE, about the importance of providing the facts and addressing concerns.

This was followed by consultant haematologist, Dr Rachel Kesse-Adu, sharing the data we have so far on COVID-19 and sickle cell, collected from sickle cell centres from around the country.

Next, Dr Abbie Wickham (clinical psychologist) gave a presentation on how to make difficult decisions about your health.

Finally, we ended with an open Q&A section from sickle cell patients Lynette, Kojo, Zainab and Laurel to ask any questions they had about getting the COVID-19 vaccine.

## Sickle Cell Patient Stories

Finally, we joined with Dr Rachel Kesse-Adu (consultant haematologist) to talk to five sickle cell patients about their experiences of getting the COVID-19 vaccine.

With the COVID-19 vaccine being rolled out, lots of people got in touch to ask if anyone with sickle cell has had the vaccine.

We spoke to Emma, Liz, Ayo and Ansella about their experience, why they got the vaccine and if they had any side effects. We also heard questions from Anthony, a sickle cell patient who is yet to have the vaccine.

All of these videos and other COVID-19 information and guidance can be found on our website:

[www.sicklecellsociety.org/coronavirus-and-scd/](http://www.sicklecellsociety.org/coronavirus-and-scd/) as well as on our YouTube page.

# Living with Sickle Cell through the Lockdown

By Basil Nigel Bramble

Where can I start? 2020 wasn't a good start. I went to my friend's mother's funeral at the end of January 2020 and my cousin's husband was in a hospice with cancer and I was very close to him. My stepmother wasn't well and died in early February, a few days after my friend lost his mother and my cousin's husband died.

This was such a shock for me and the family. I went into a sickle cell crisis with all this going on for me and have to have regular treatment each month at the hospital. It was taking its toll. I just don't know how I made it through.

A month after, we were hearing about this coronavirus more and more. It turned out to be pretty serious and we had to go into a lockdown. I was frightened as I suffer from a serious illness myself and many people have found it very very difficult. Sadly, many people died of coronavirus and many people just couldn't take it and sadly took their lives. It's so sad and it's still very difficult and challenging.

I think it's going to be a long time that I, like many

people who have health issues, will have to shield. We have had to travel to and from hospital for life saving treatment and many of us have felt frightened to travel on the bus or tube of fear of catching this dreadful virus.

In June, I was involved in a recording for NHS 70 about living with an illness during the coronavirus pandemic. I also did various recordings for the Sickle Cell Heritage Project on people living with sickle cell who were born before and during the fifties. This exhibition can be seen online here:

<https://www.bcaexhibits.org/exhibits/our-journey>

In November, I was still struggling through, still having my treatment and trying to stay positive. Things I have done during the lockdown whilst at home, reading a little bit more and a little exercise each day and I'm a gamer so playing games on my PS4 and I'm lucky to have a garden. These things have helped but some days it's very challenging mentally for me. I do suffer from depression but I have a good family and some good friends and that helps a lot. As long as it takes, I'll continue doing what I've been doing and hopefully the normal times will be back soon.

As I volunteer for a leading eye hospital here in London, every month we have Zoom meetings with management and other volunteers. That's been really nice because most of us just haven't been able to volunteer due to this pandemic.

We have now reached 2021 and we are in lockdown again and it's very challenging and hard for people, businesses and especially our wonderful National Health Services. Wow they all deserve a medal!

I do hope I can stay positive until it's over. It will probably be a different world but a little bit normal is better than what we have at the moment.



Basil Nigel Bramble



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/](http://www.sicklecellsociety.org/membership/)  
[www.sicklecellsociety.org/donate](http://www.sicklecellsociety.org/donate)  
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Telephone: 02089617795

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