sicklecell

SICKLE CELL SOCIETY

THE NEWSLETTER OF THE SICKLE CELL SOCIETY

AUTUMN 2021

In this issue:

Inquiry into Sickle Cell Care
Our Journey Our Story Exhibition
Potential new treatments
Plus, so much more…

www.sicklecellsociety.org

Contents

Sickle Cell Society Newsletter Autumn 2021

Cover
Bola raising awareness at the 'Made a Way' event as part of the Give Blood, Spread Love, England project

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

Introduction

We hope that you and your loved ones are keeping safe and well. COVID-19 continues to be at the forefront of our thoughts over the last six months but this hasn't stopped the vast amount of work we have been doing virtually (and a few bits in person).

Ensuring that you have up-to-date and accurate sickle cell COVID-19 information has been one of our priorities. Our website has continually been updated with the latest information including specific guidance on sickle cell, data from the National Haemoglobinopathy Panel and vaccine information.

In April, we heard the results of the inquest into the preventable death of Evan Nathan Smith. The news rightly generated a lot of anger within the Sickle Cell Society, sentiment we know is reflected across the sickle cell community. As part of the response (alongside meetings with North Middlesex Hospital, North Central London HCC, NHS England, Department of Health and Social Care, and the National Haemoglobinopathy Panel) we worked with the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG) to launch an Inquiry into Sickle Cell Care.The Inquiry launched in May and saw evidence hearings in June. The inquiry looks to examine the care sickle cell patients receive, seek to identify why care for sickle cell patients is too often sub-standard, and look to ensure that recent tragic cases lead to national change to ensure that such failings are not repeated in future. You can read more about the Inquiry later in the newsletter.

We were also deeply saddened to hear the news of Richard Okorogheye's passing. We reached out to his family, and have been working with them on how best to support

them and honor Richard by raising awareness and blood donors.

We were delighted to be able to open the doors on our sickle cell exhibition, Our Journey Our Story: History and Memory of Sickle Cell Anaemia in Britain 1950-2020. The exhibition had previously been hosted online on the Black Cultural Archives (BCA) website. On the 21st May at the BCA, the exhibition was finally opened for visitors. The exhibition is part of our wider Heritage project, which looks to archive and celebrate sickle cell's history in the UK and is now hosted virtually again at our website.

Raising awareness about the history of sickle cell and healthcare in the UK is an important way to remember those who have contributed greatly to improving care and can help shape how we can continue to make progress. Our NHS Engagement Lead, Iyamide, was delighted to be interviewed by the Young Historians for their project: 'A Hidden History: African women and the British Health Service in the 20th Century'. You can read all about the project later in this newsletter. Iyamide will also be providing a detailed update on the Screening Project, including information on the 'Parents' Handbook' and 'Paediatric Standards'.

In this edition of the newsletter we are also sharing a range of exciting potential new treatments for sickle cell. As you will be aware, there are only a few treatments currently available for sickle cell patients. We are always looking to see more treatments become available to patients in the UK. as well as exciting news about the first sickle cell treatment in over 20 Years.

We loved celebrating with everyone over World Sickle Cell Day on the 19th June. It was great to see so many people dressed up in red and sharing awareness videos and graphics with friends and family. A massive thank you to everyone who got involved and raised money for us, and to Miffy for their ongoing collaboration, donating money with their sickle cell plush toy and their brilliant sickle cell awareness video which we shared on our social media channels.

Celebration and awareness was also the theme of our fundraising gala in partnership with Reverse Psychology London. 'Rise Up for Sickle Cell' was a luxurious evening of music, art, fashion and more, hosted in the exclusive Home House private members club. You can read all about the performances, fashion show and fundraising efforts later on.

We hope you enjoy reading the newsletter. As always, you can be kept up-to-date with all of our work by following us on social media and by checking out our website. Keep a particular eye out for our fourth Sickle Cell and Coronavirus (COVID-19) Live Q&A coming in early November.

We know that the impact of the pandemic is ongoing, but we hope that with the vaccine's wide distribution things will begin to look more hopeful.

Much work is needed to be done and we will continue to be at the forefront of providing support to the sickle cell community. Thank you for all of your support, and we look forward to continuing working with you.

John James OBE Chief Executive and
Kye Gbangbola Vice-Chair & Treasurer

John James OBE *Kye Gbangbola*

Inquiry into Sickle Cell Care

Recent high-profile examples of failings in care for people with sickle cell disease have led to growing awareness of the challenges sickle cell patients still too often face in receiving appropriate care. It is clear from testimony from healthcare professionals, sickle cell patients and their families over many years that these recent high-profile cases are not isolated incidents.

In response to this, the All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG) with the Sickle Cell Society as secretariat, has launched an Inquiry into Sickle Cell Care. The inquiry is examining the care sickle cell patients receive, seeking to identify why care for sickle cell patients is too often sub-standard, and looking to ensure that recent tragic cases lead to national change to ensure that such failings are not repeated in future.

The inquiry was chaired by SCTAPPG, Chair Pat McFadden MP, with participation from the group's officers and other interested parliamentarians. The inquiry collected evidence on sickle cell care from patients, patients' family members, clinicians, commissioners and other relevant stakeholders and is in the process of producing a report that will make specific recommendations for action by the Department of Health and Social Care, NHS England, the Nursing and Midwifery Council and others.

Collecting Evidence

In order to gather this evidence, the SCTAPPG invited submissions of written evidence in May and June. The call for evidence was shared as widely as possible, including to our members, on social media and our website, to sickle cell support groups, to Haemoglobinopathy Coordinating Centres, to relevant NHS Trusts and to other stakeholders.

As well as written evidence the inquiry also held three virtual evidence sessions. The evidence sessions took place on the 9th, 16th and 30th June and saw evidence from sickle cell patients, carers, and family members, as well as healthcare professionals both directly involved in sickle cell care and with wider managerial roles within the NHS. One session also saw a presentation of evidence from the parents of Evan Nathan Smith whose preventable death sparked the inquiry.

At each of the inquiries, Sickle Cell Society staff and trustees as well as a range of MPs asked important questions about the evidence, the care sickle cell patients are receiving, and what has already been put in place to address the issues mentioned.

The report is due to be published in October and will be shared widely amongst our members, on social media and with the press. We hope that the findings and recommendations of the report will lead to permanent, national chage and ensure that the sickle cell community will not see such tragic failings again.

Bola on Stage (29th July)

…is the Society's blood donation project. The project works with black-heritage communities to: raise awareness of the need for ethnically matched blood to treat people with sickle cell; help potential donors feel confident about giving blood, and recruit new black-heritage people to the blood donation register.

Engaging with communities is at the heart of Give Blood, Spread Love, England. Here are 10 ways you can get involved:

1.Sign up

If you're not a current blood donor and would like to help people with sickle cell have easier and swifter access to ethnically matched blood, you can sign up via our registration link. While most people can give blood, including those with sickle cell trait, we understand that not everyone is eligible to become a blood donor. If you can't donate due to having sickle cell, or for other reasons, we still need you! Support us by encouraging your friends, family and colleagues to register, simply share our link and let them know that signing up is quick, easy and confidential.

2. Share

We know that some people need more information to feel confident about giving blood. Our social media and website pages have a wealth of information, links and films about what happens during a blood donation session and the life saving impact of donated blood. Sharing accurate information about blood

donation is a very powerful way to support this work. (For example, did you know that when you go to give blood that the taking of the blood only takes ten minutes, maximum? Or that a few weeks after you've donated you are told the hospital where your blood has been used?)

3. Invite us

If you are part of an organisation, workplace or worship group with a majority of African and Caribbean heritage members, you can ask us to deliver a face to face blood donor recruitment session. You'll need to meet a few criteria, including offering access to a large audience. Ask us for more details.

4. Volunteer

We're always on the lookout for more volunteer team members. Whether you'd like to be a Give Blood Squad member (largely virtual) or a Community Advocate (largely community-based), we want to hear from you. We are currently seeking volunteers with sickle cell who have occasional or regular blood transfusions, people in England, but outside of London, and more male team members. You'll need to successfully complete our recruitment process and commit to actively recruiting new donors. Ongoing training, support and team spirit provided!

5. Record

Are you a famous face? Social media influencer? Community leader? Our social media channels feature people from our target communities supporting the work of our project. Record a message supporting Give Blood, Spread Love, England and share with us via Instagram. Your video could explain why you've registered as a blood donor, show you giving blood, or share why donated blood is important in your life. Your message needs to be around 30 seconds long, and we can help with wording, if you'd like us to.

6. Organise

Would you like to arrange a group blood donation session for your friends, family or colleagues? We can provide you with information and guidance on how this can be done (in line with the Covid 19 rules of donation centres), and share images of the day via our social media. This is a great way to demonstrate your organisation's/group's support of sickle cell and blood donation, and share in a life-changing activity with those close to you.

Volunteer Jackie at a donor recruitment event

7. Pledge

Need some external motivation and reminders to support our cause? Get involved in our ' I pledge…' campaign and tell us what you pledge to do to get more black-heritage people to register to give blood. Send us your one-line pledge and the date you will do it and we'll check in with you about your achievements and celebrate them on our social media. You can send this to us via Instagram, Twitter or email. Your pledge could be, 'I pledge to register as a blood donor and share my experiences of giving blood with the Sickle Cell Society', or 'I pledge to sign up 10 male friends to the blood donation register.' (Men are underrepresented among those giving blood and are especially needed as they can give more frequently than women.)

8. Ask!

If you have questions or concerns about blood donation that stop you donating or encouraging others to give, please let us know. Our project is committed to addressing worries or barriers that people may have about blood donation. We will answer your questions or seek out more information, if needed. No question is too silly or strange.

9. Play a Part

Our Play a Part campaign is targeting sports and active hobby groups to work with us on blood donation, get in touch if you want to share our message and recruit new donors with us through your group.

10. Follow

Following us on social media is a great way to learn about blood donation and find even more ways to get involved:

Instagram – @givebloodspreadlove
Twitter – @givebloodlove
Sign up to save a life: bit.ly/scsgiveblood
Share our resources: https://www.sicklecellsociety.org/blooddonation/

Contact us:

Tracy Williams, Project Manager, **tracy.williams@sicklecellsociety.org**
Olivia Anastasiou, Digital Marketing Officer, **olivia.anastasiou@sicklecellsociety.org**

A Visit to the Sickle Cell Society Exhibition on the History of Sickle Cell in the UK

By Iyamide Thomas, NHS Engagement Lead

On Friday 16th July, I decided it was time to visit in person (as opposed to online) the Society's exhibition at the Black Cultural Archives (BCA) which had been co-curated by my work colleague Alinta Sara. The COVID-19 pandemic had delayed it's BCA run and its initial closing date had now been extended to 31 July. My colleagues Valerie Oldfield (Sickle Cell Society Helpline Officer) Nkechi Anyanwu and Patience Ologe (Service Manager/Clinical Lead and Case Manager/Specialist Nurse respectively of SE London Sickle Cell & Thalassaemia Centre) all decided to be part of my 'posse' as not only would it be great to see the exhibition, but it would also be great to see each other face-to-face after so many months! Alinta would also join us and give a 'curator's tour'.

A UK first, '*Our Journey Our Story'* is an exhibition on the history of sickle cell, the NHS and the Black British community. Through testimonies and experiences of people living with sickle cell, health professionals, photographs and archives, it unveils the history of sickle cell campaigning to make sure that sickle cell was recognised by medical professionals and how treatment has evolved.

This is what BCA Managing Director, Arike Oke, had to say: "*This is such an important exhibition telling a story not often shared beyond the Black communities, even though sickle cell affects other racial groups. We're proud to work alongside the Sickle Cell Society to raise awareness on this important subject."*

If you missed seeing this great exhibition at the BCA, all is not lost as its online version can be accessed from the Sickle Cell Society website at:
https://www.sicklecellsociety.org/our-journey/
The Sickle Cell Society archives and oral histories collected as part of curating the exhibition will be going to the world renowned Wellcome Trust archives, becoming a legacy for generations to come!

Valerie, Iyamide and Alinta stand by image of sickle cell pioneers including one of the Society's founders Dame Elizabeth Anionwu

Nkechi, Iyamide and Patience by sickle cell service user stories and images

Saying Goodbye to Professor Simon Dyson

Long time Scientific Advisor for the Sickle Cell Society, Professor Simon Dyson, has stepped down from his role as part of his wider retirement. Professor Dyson has been a vital part of the Sickle Cell Society, providing support on documents and guides including *"Sickle Cell Work and Employment – A Guide for Employers and Employees on Work, Employment and Sickle Cell Disorder"* and *"A Guide to School Policy"*, as well as talks and lectures on sickle cell and the social sciences, and further advice and scientific support.

As part of his retirement Professor Dyson is raising money to support our work. You can find out more and donate here: www.justgiving.com/fundraising/simon-dyson-retirement

New Scientific Advisor: Karl Atkin

Joining our team as our new scientific advisor is Professor Karl Atkin, FAcSS. Karl Atkin is a professor of sociology at the University of York. He re-joined York in 2005 after various posts at the Universities of Bradford and Leeds (including Director of Primary Care Research).

He is a medical sociologist whose research focuses on health and social care in multicultural societies. This including understanding the social consequences of various long standing, chronic illnesses. He has researched the experience of those with sickle cell disorders and their families for over 35 years (https://www.york.ac.uk/sociology/our-staff/academic/karl-atkin/).

Karl is a member of National Institute of Health Research Panel for Advanced Fellowships and for ten years was Chair of Public Outreach for the NHS National Screening Committee (Sickle Cell and Thalassaemia). He has been a trustee of several voluntary organisations, including Juniper Communities and Leeds Health for All.

Karl contributed to 'Standards of Care for Adults with Sickle Cell Disease' (2018) and Policy Press have recently published his co-authored book '*Understanding Race and Ethnicity*' (2020). He wrote the *Politics of Sickle Cell and Thalassemia* (Open University Press) with his good friend Elizabeth Anionwu. He has also worked extensive with his other good friend, Simon Dyson, with whom he edited *Genetics and Global Public Health: Sickle Cell and Thalassaemia* (Routledge). Karl is an elected Fellow of the Academic of Social Sciences.

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

Legendary British singer-songwriter Roachford headlining the event

SCS patron, Kym Mazelle, socialising with one of the catwalk models

Stella Mae modelling her fashion line with the other catwalk models

Getting ready for the auction

Relaxing in a beautiful venue

Catching up with friends over a glass of bubbly

Enjoying the music of DJ Femi Fem

Rise Up for SICKLE CELL

On Thursday 22nd July, Reverse Psychology London in partnership with the Sickle Cell Society were excited to host Rise Up For Sickle Cell, a glamorous evening of celebration and fundraising.

Hosted in the exclusive Home House private members club, Rise Up for Sickle Cell was a luxurious evening of music, art, fashion and more.

Upon arrival, guests were welcomed to the iconic venue with complimentary drinks and delicious canapés, whilst they perused the specially selected artwork on sale.

The evening was headlined by an exceptional performance from legendary British singer-songwriter Roachford, as well as music from Mi-Soul Radio and Young Disciples' very own DJ Femi Fem.

During the evening, guests enjoyed even more drinks and canapés whilst being entertained by the spectacular fashion of Reverse Psychology London by STELLA MAE and SOBOYE.

The night then moved on to the fundraising auction, where guests were able to bid on a fantastic range of artwork and prizes before the event was rounded off by music and dancing.

A massive thank you to everyone who celebrated with us and helped raise money and awareness for sickle cell.

We would also like to thank Stella Mae and Clare Caisley Routh for organising this fantastic event as well as Vertex Pharmaceuticals whose sponsorship has enabled this event to happen.

A special thank you to Roachford and DJ Femi Fem for bringing their brilliant musical talent, and the models and make-up artists for provided the fabulous fashion show.

Thank you to all the artists who donated paintings including Moussa Sanogo, Anthony Padgett, Eleni Gagoushi, Francesca Marcenaro & Shirley Anne Steer and Simon Chinnery as well as to Bonhams' Auction House for hosting the auction, Colin Sheaf the Deputy Chair for the Asia Art Market and London Beauty Artists (LBA).

Finally, a thank you to everyone who donated to the auction including Sergios and Blush Nails.

A Hidden History: African Women and the British Health Service

By Iyamide Thomas – NHS Engagement Lead

A team of individuals aged 16 – 25 are encouraging young people of African and Caribbean heritage in Britain to become historians. Known as the 'Young Historians', their non-profit organisation has worked on projects covering new ground and often overlooked histories. Their latest project '*A Hidden History: African women and the British Health Service in the 20th Century*' seeks to redress the imbalance in the reporting of African women's long history of working for the health service in the UK, as past narratives have often only focussed on Caribbean contributions from the 'Windrush Generation'.

Throughout summer 2021, the Young Historians conducted online launch events which showcased the project's learning outputs including a documentary series, an online exhibition, eBooks and podcasts. I am pleased to say that I was interviewed for the project together with several health professionals from the world of sickle cell including Dame Elizabeth Anionwu (a founder and patron of the Sickle Cell Society), Dr Olu Wilkey, (Paediatric Consultant, North Middlesex University Hospital) and Dr Lola Oni (Service Director, Brent Sickle Cell & Thalassaemia Centre).

The interviews with ourselves and many other African health professionals can be accessed on the exhibition website below. The website gives an amazing history of African women's contribution to health in Britain even before the formation of the National Health Service (NHS). Well done to the Young Historians for the tremendous work that must have gone into making this project a reality and success!

https://www.younghistoriansproject.org/research-hub

Dame Elizabeth Anionwu with a group of Young Historians

Young Historians take part in a history skills workshop

Photos: Young Historians

World Sick

Winston

Rita

Iyamide Sickle Cell Society NHS Engagement Lead

Emmanuel (USA)

Conrad

Amanda

As we are sure you will be aware, the 19th June is World Sickle Cell Day. Each year we join with people around the world to raise awareness of sickle cell. With most people keeping safe at home, this year we celebrated by joining the community virtually.

A History of World Sickle Cell Day

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

Social Media Awareness

Leading up to the day, we created a social media pack to help other people celebrate and raise awareness. The pack contained a range of key facts about sickle cell as well as graphics which could be shared on social media and in group chats.

le Cell Day

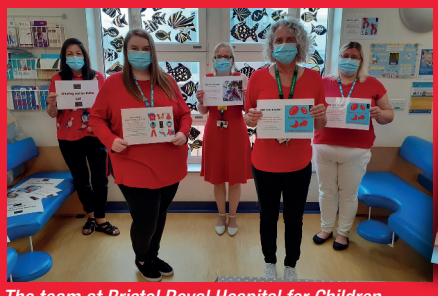
Kayode

June (USA)

Daphne (USA)

Cordelia and Kathryn

Melbourne (USA)



The team at Bristol Royal Hospital for Children

The pack also contained information on how to raise money for sickle cell on the day and information on getting involved in our Wear Red for Sickle Cell campaign.

Wear Red for World Sickle Cell Day

Building on the success of last year, we joined with people around the world to wear red on the 19th June. Wearing red is a great starting place for conversations about sickle cell and can be a great entryway into raising awareness. A massive thank you to everyone who shared or tagged us in pictures.

Miffy

Illustrations Dick Bruna © copyright Mercis bv, 1953-2021

Miffy – the classic bunny character created by artist Dick Bruna – is to help raise awareness and funds for children in the UK with sickle cell disorder.

Launched on this year's World Sickle Cell Day (19 June), the partnership comprises a campaign video featuring Miffy plus a special range of soft toys which will be sold via the Miffy Shop, with 10% of sales to be donated to the Sickle Cell Society.

Plus, download this free Miffy and Melanie colouring sheet and get your favourite crayons at the ready to help raise awareness for sickle cell disorder.

Find out more about the Miffy and Melanie sickle cell plush toys and the colouring sheet at our website: **https://www.sicklecellsociety.org/miffy-sickle-cell-partnership/**

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/**

Update on Screening Project

Iyamide Thomas, NHS Engagement Lead, Sickle Cell Society

First, The Good News!

In 2018, the NHS Sickle Cell and Thalassaemia Screening Programme commissioned a three year 'Engagement Project' to work in collaboration with the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) to help ensure that their service provision was underpinned by service user needs. Well, the good news is this latest contract has now been renewed for a further two years, showing that the Societies continue to be an invaluable resource to the Screening Programme. Through our flexible, culturally sensitive work within communities affected by sickle cell and thalassaemia, the SCS and UKTS can gain trust and generate useful insights from service users that can inform the Screening Programme's policy and practice, whilst also helping them address any existing inequalities.

Project Update

In our last newsletter (Spring 2021) I gave a comprehensive interview that included the Engagement Project and some of the current screening work. Here is a brief update on some of that work:

'Parents' Handbook' and 'Paediatric Standards'

On 28th January 2021 we launched the following publications online and these are now available in hard copy:

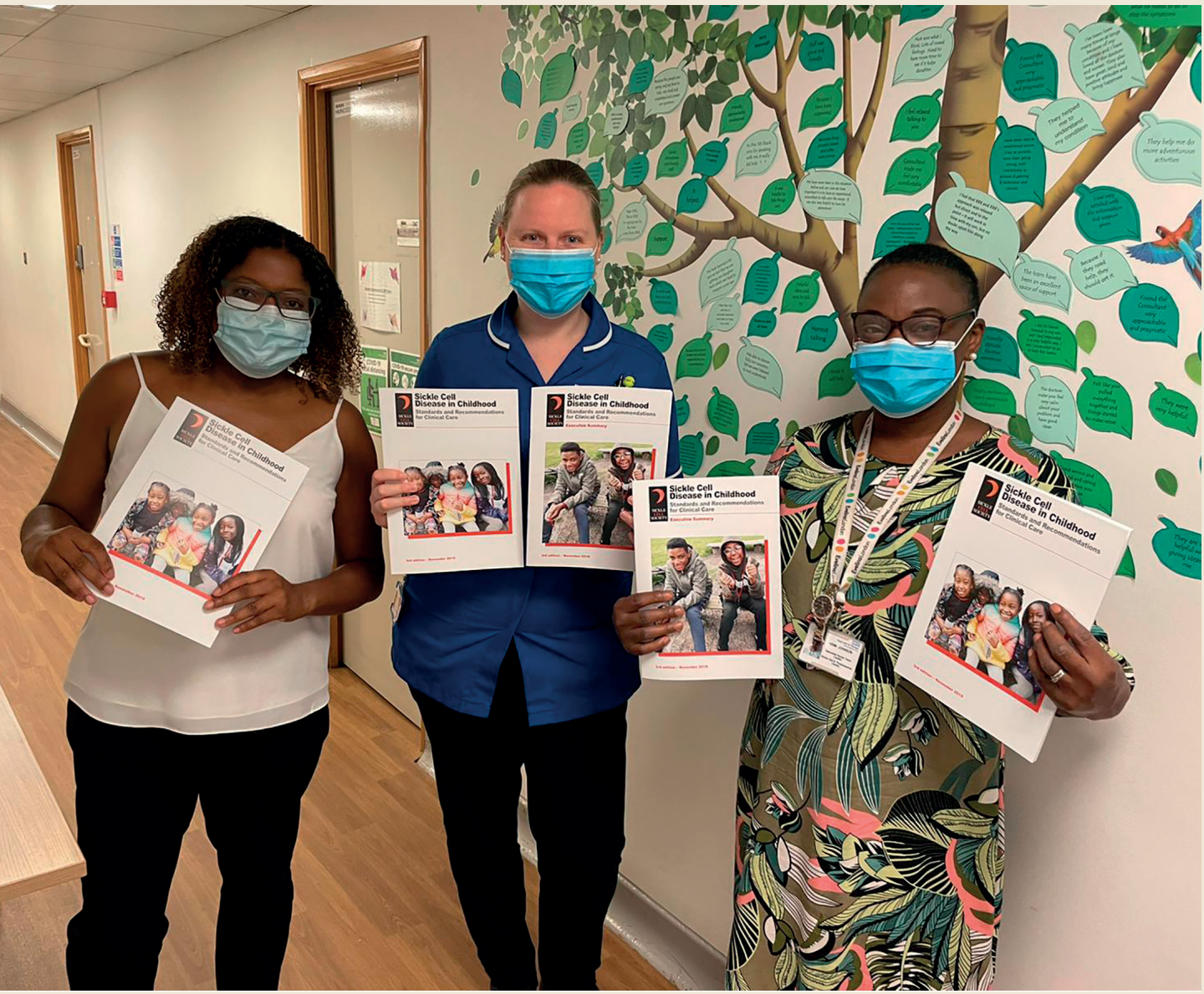
'A Parent's Guide to Managing Sickle Cell Disease' (4th Edition) –' Parents Handbook'
'Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care' (3rd Edition) which has a full document and an 'Executive Summary' – 'Paediatric Standards' The publications are currently being disseminated to the various hospitals, sickle cell & thalassaemia centres and other relevant health professionals via the ten Haemoglobinopathy Coordinating Centres. Hard copies will also be available from the Society in October when staff return to our offices which are currently being renovated. However, the publications are also on the Sickle Cell Society website:
https://www.sicklecellsociety.org/resource/parentsguide/
https://www.sicklecellsociety.org/resource/paediatricstandardsresource/

E-Learning Resource

The Societies have been helping the Screening Programme revise its E-Learning resource for health professionals working in the screening pathway. The resource will include filmed interviews with the Societies. We had thought filming would be by Zoom, however on 17 June we were able to film face-to face at the UKTS offices – all COVID-19 safety measures in place of course! These interviews will be edited for the E-learning resource such that they show the Screening Programme by working with the Sickle Cell Society and UK Thalassaemia Societies are addressing inequalities that might arise due to culture, stigma, language, religion, as the Societies can feedback the individual user needs which the Screening Programme cannot access, since they have no direct relationship with service users. Some of the extended interview which includes the outreach the Societies do on behalf of the Screening Programme will probably be featured separately and called 'Society Stories'.

Focus Group Consultations

SCS / UKTS have started conducting the online focus groups which will give valuable service user feedback on: 1) the reporting methods used to deliver newborn sickle cell carrier result 2) the methods used to deliver new-born positive (i.e., baby has the condition) screening results for sickle cell and thalassaemia. Each Society is to hold three focus groups: two each with mothers and fathers whose children are under three years old and one each with individuals who have not yet had children who might be at risk of having a child with sickle



King's College Hospital staff show off their 'Paediatric Standards'

UKTS, SCS and Screening Programme socially- distanced photocall at E-Learning filming

cell or thalassaemia. To date SCS has held a focus group with 10 mothers of children with sickle cell and UKTS has held a focus group with 3 mothers. These focus groups provided a wealth of useful information on how health professionals communicated newborn results (good and bad) which the Screening Programme can use to make relevant improvements.

We are now looking for fathers and individuals with sickle cell or thalassaemia trait who have not yet had children to take part in the remaining focus groups.

Please contact me if interested: iyamide.thomas@sicklecellsociety.org

(For more comprehensive updates on the Screening 'Engagement Project' please see the annual progress reports on the Sickle Cell Society website).

The HOPE trial

Interview with Kathleen by Oke Obiuwevbi, medical student of Anglia Ruskin University

INTRODUCTION

Kathleen, 56, retired IT teacher, shares her experience of having Sickle Cell Disease and what it was like being part of **the HOPE Trial**. **The Hope trial** was an international, randomised, double-blind, placebo-controlled, phase 3 trial looking at the use of *voxelotor* drug in 274 patients with Sickle Cell Disease at 60 clinical sites in 12 countries including UK between 2016-2019. *Voxelotor* is a new tablet, developed to protect patients with Sickle Cell Disease from vaso-occlusive pain crises. Based on this trial *voxelotor* has been approved by the US Food and Drug Administration for the treatment of sickle cell disease in adult and adolescent patients (aged 12 years and older) at a dose of 1500 mg orally once daily. Its approval will be considered towards the end of 2021 in EU and 2022 in UK. and is already available on compassionate use in UK.

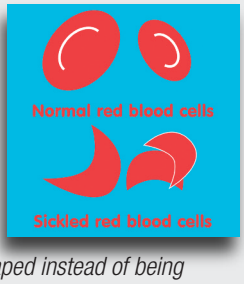
OKE: What is life like living with Sickle Cell Disease?

KATHLEEN: When I was born, they didn't know that I had Sickle Cell Disease. It was only after I had been hospitalised following a stroke crisis which resulted in me learning how to walk again did my family and I become aware of the diagnosis. Though, I'm the only one in my family that has Sickle Cell. I went to school in Sierra Leone, West Africa and because my family had private medical care, treatment was easier for me.

I came to the UK in the 80s and started seeing Haematology Consultants at Guys' and St Thomas' hospital in London who took over

my care. Growing up, I'd been given set life expectancies – I was constantly told that I wouldn't make it to my 16th, 18th or 21st birthday. It was expected that you would die before reaching these milestones and I always knew that. It was almost as if you were living with a death wish hanging over you. Since then, I've been trying everything I can to stay alive. I remember a conversation I had with one of the doctors who said that if I didn't have children by my 28th birthday, I shouldn't bother. But then I got married, had my first son at 33 and then my second son before my 41st birthday.

CRISIS



Sickle cell disease is an inherited blood disorder that causes your red blood cells to become sickled/crescent- shaped instead of being round under circumstances of the low level of oxygen in blood. These "sickled" cells don't live as long as healthy red blood cells and get trapped in blood vessels resulting in painful episodes of chronic anaemia as blood flow is reduced. These obstructions are also known as vaso-occlusive pain crisis and can lead to organ damage and even death.

OKE: What does a crisis feel like?
KATHLEEN: Terrible – absolutely terrible! I used to pray that I would die when I was having a crisis because I was in so much pain. During the 80s, when I was younger, when you would go to the hospital, you'd find a lot of patients in **vaso-occlusive crisis** on **pethidine** pain relief who were addicted to the drug. (Luckily this risk has been recognised and **pethidine** has been completely banned from pain management of sickle cell disease in UK).
I knew I didn't want that to happen to me, so, I would always say no to the drug and just bare the pain. The pain was unbelievable. I have never had labour pains, but people compare it to having labour pains. When you're having a pain crisis, it comes in waves. When it comes, I would hold my breath, but I found that that actually makes it worse, because of the already reduced blood flow. Having said that, when it comes to having a crisis versus leg ulcer's – I would take a crisis any day because the leg ulcers affect my self-esteem. The crisis is just pain and it's something that you get used to living with. When I used to work, I'd wake up in the morning with a crisis and I'll take the slow-release morphine, drive to work, work all day for 6-7 hours and then go to bed. But that meant that my family weren't seeing me as my husband would then take over the care. Having a crisis is hard, I wouldn't wish it on my worst enemy – it's painful. It's just unbearable pain where I'm living on morphine until the pain ceases.

There was one occasion where I had a crisis, and I went into the hospital but then I ended up going into a coma. They said it was due to the trauma from an ectopic I'd had previously that had caused it. When I was in the coma, they called my husband and told him to prepare for the worst because they weren't sure if I would make it, but I did – thank God! I was with my son, (who at that time was 2) who saw the whole thing and even till this day, he still checks on me when I'm sleeping to see if I'm alive. .

VOXELOTOR AND THE HOPE TRIAL

Voxelotor is a new tablet. It works by directly binding to sickle cell haemoglobin and preventing it from building up long polymer molecules during hypoxia, a low level of oxygen in blood. These polymers are like very long sticks elongating and changing the shape of red blood cell from round to sickle. Sickle cell haemoglobin is caused by a single gene inherited mutation on chromosome 11. People with sickle cell disease inherited abnormal genes from both parents. There are a few types of sickle cell anaemias depending on the combinations of abnormal genes on chromosome 11 like genes for Haemoglobin S, Haemoglobin C or sometimes combined with a Thalassemia gene.

OKE: How did you find out about the trial?
KATHLEEN: In 2014, I retired from work because I was having so many crises and I was being stressed at work. I had a crisis and went in and had a consultation with one of my doctors who said *'we have a trial drug voxelotor that you could take, since you are already on hydroxyurea, you can go on the HOPE trial'* which I did, so I started the trial in December 2017. (**HOPE** is an acronym created from description of how **voxelotor** works – the **H**emoglobin **O**xygen Affinity Modulation to Inhibit HbS **P**olym**e**rization).
It was a randomised trial. And now we know there were 274 people participating in this trial from all over the world with sickle cell disease randomly assigned to the three groups: 90 people to **voxelotor 1500 mg** group, 92 patients to the **voxelotor 900 mg** group and 92 people to the **placebo** group.

OKE: What was it like being on the trial?
KATHLEEN: I had to keep a diary and had to take the medication on a regular basis. I was going in every 2 weeks at first and then later every 4 weeks for check-ups. Every time I went, I had an ECG done *(a test that looks at your hearts electrical activity*), bloods and the other usual checks – it was very detailed. It was good because you knew that they were looking out for you. They'd ask you lots of questions: if you'd had a crisis, what level of pain were you experiencing, how were you feeling emotionally etc. I thought it was very effective. Although, it did eventually become a bit monotonous – because it did reach a point where it felt like you were almost ticking boxes as I had been going for visits for so long.

I did experience a few of the side effects, which I was made aware of prior to taking part in the trial. Anytime you experienced a side effect you were told to report it. On a few occasions I had to reduce the dose that I was given before it was titrated back up to the original dose. Some of the side effects I did experience included having the runs and leg ulcers. However, even with that it, didn't stop me from wanting to continue with the trial because I knew that this was the pathway to staying alive. I want to see my kids grow up. I saw my eldest graduate the other day and he's also started his masters. I want to see all those milestones, so yes, I am happy to be on the drug because- it's given me a lifeline!

OKE: How did you know you were on the actual drug and not only on placebo?
KATHLEEN: The HOPE trial was a double-blinded study, which meant that neither the patients nor the clinicians knew what treatment the patients were being given until after the trial had ended. I only worked out that I was on the active drug not placebo on one occasion when I learned my result of haemoglobin was almost normal, close to 120 g/L. My usual steady state haemoglobin before used to be around 80g/L.

OKE: How has life been since the study?
KATHLEEN: It's coming to 4 years since I was part of the trial. Although it has ended, I'm able to continue taking voxeletor alongside my other regular medication: **hydroxyurea** (to protect me from vaso-occlusive crises in different ways in cooperation with voxelotor), **folic acid** (vitamin from green vegetables to nourish my ▶

bone marrow, the organ producing my blood cells), **cefalexine** (low dose antibiotics to protect me from sepsis due to auto-splenectomy i.e. my spleen has been completely damaged by previous recurrent sickle cell crises), **candesartan** (to protect my kidneys affected by previous vaso-occlusive crises) and **alendronic acid** (to protect my bones from osteoporosis).

I'm healthy, I don't have crisis' the way I used to, and I have a very good quality of life. For me, it's all about your quality of life. I haven't had a crisis where I've needed to be hospitalised for a long time. I wish I was on this drug when I was in my 20s, because I wouldn't have to live with the lung and kidney problems that I'm having now due to complications of having Sickle Cell Disease. I'm on oxygen at night and I can't travel without oxygen. These are a lot of complications I could have avoided if I'd been on this drug a lot sooner. So, I would definitely recommend this drug for young people if they are able to get on it because it could have prevented all the complications that I'm currently experiencing now.

"Please note that this is a personal opinion and that the Sickle Cell Society would always recommend speaking to your specialist nurse or consultant about all of the options and finding what is right for you."

TRY AND FIND YOUR PURPOSE

OKE: Is there anything else you'd like people to know about living with Sickle Cell?

KATHLEEN: If you're young person with SCD – it's a manageable disease. Eat properly and just be careful with what you do. Just look after yourself. If you see me on the street, you would never know that I'm a patient with Sickle Cell Disease. Unless I told you before, you wouldn't know. I always say: *it's mind over matter*. I used to go to support groups and there'd be patients complaining about how hard life was having this disease – don't get me wrong life is hard, but it's HOW you deal with it! It's a lot of minds over matter! *Try and find your purpose* – it's easier said than done, I know, but find something you aspire to and live for that. We just have to find ways to go about things. For example, I've found that rather than paying £9.35 for every prescription I'm given – it's easier to pay annually as it's much cheaper that way.

If you've decided that you're going to live – you have to fight this – that's always been my motto. I'm 56, and I'm hoping to see my 70th and 80th birthday. My youngest son is 15 and he's already told me the songs that we're going to dance to at his wedding for his mother-son dance. I've got all these things to aspire to and that is what will give you the hope to fight

OKE: Thank you so much for taking the time to talk to me and share you experience.

KATHLEEN: I'm happy to talk about my experience, I'm happy to go forward to schools, wherever they need me. I'm happy to be out there, because at the end of the day, if everybody is educated, not only does it help me; it helps my children, and my children's children.

1st August 2021

Oke Obiuwevbi

4th Year Medical Student

School of Medicine, Anglia Ruskin University

YOUNG CARERS

Imago Young Carers support more than 10,000 young people aged 5-24 across Kent, East Sussex and the London Boroughs of Southwark, Havering and Bexley. Young Carers are children who support a parent or family member who is struggling with a physical illness such as sickle cell or a mental illness or substance misuse. During the pandemic and lockdowns the role of Young Carers was more important than ever.

Imago Young Carers work with schools, communities, statutory and voluntary agencies to identify and support hidden Young Carers. Following assessment, Imago Young Carers offer a range of short-term interventions including signposting, one-to-one support, in-school support and workshops. Their aim is to highlight the positive impact of being a carer such as increased resilience, empathy, non-judgemental attitudes, and caring nature.

"Imago Young Carers support has helped me to understand my feelings. I am much more confident and people have started to notice and make comments, and this shows I am on the right track. I am looking forward to continuing like this and not looking back!"

Young Carer, aged 14

Young Carers can often struggle to balance their caring role with other activities in their lives, sometimes facing extra pressures and missing out on opportunities that other children enjoy. Imago Young Carers aim to support these individuals in finding a sustainable balance and to provide respite from their caring roles.

For further information about support that they can provide or if you have any questions please contact the Imago Young Carers Hub:

Phone 0300 111 1110
Email youngcarers@imago.community
Or visit their website:
https://www.imago.community

Become a Member

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

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

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

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/**

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**

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/**

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**

First Sickle Cell Treatment in Over 20 Years

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

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

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

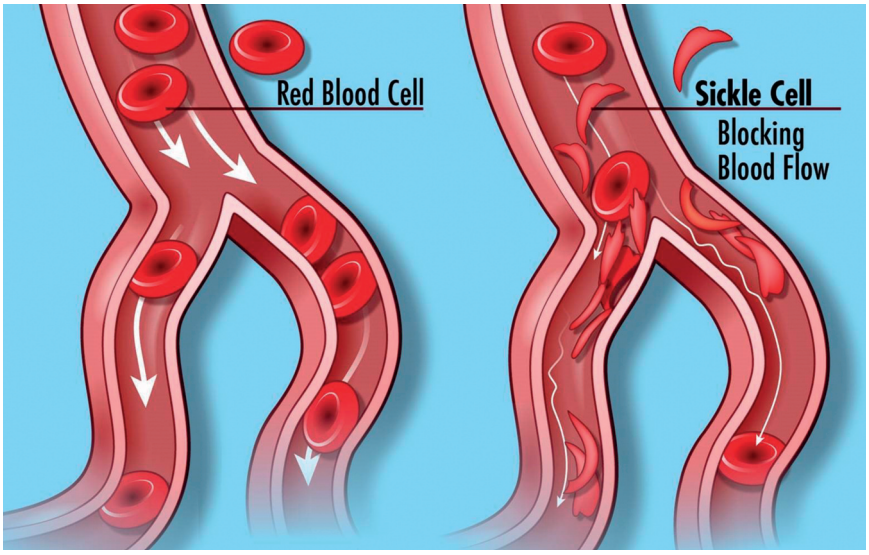
Sickle cell crises are one of the main symptoms of sickle cell. The pain occurs when the cells change shape after oxygen has been released. The red blood cells then stick together, causing blockages in the small blood vessels.

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

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

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

More information on crizanlizumab and the Managed Access Agreement will be made available on the Sickle Cell Society website soon.



Sickle Cell Blockage (Darryl Leja, NHGRI)]

Ascelus Service User Advisory Group

We are excited to be involved in the Ascelus research project, a new project focusing on developing and testing a new way of supporting people who have certain blood disorders to monitor their condition. The new approach will involve most patients in using a smartphone and/or a computer.

To help make sure the new approach is useful for as many people as possible, the research is aiming to set up an Advisory Group of about 4-5 people who are living with one of these blood disorders.

We want to recruit people with sickle cell from London, the South East and Yorkshire, who are not very comfortable with using online websites or smartphone apps.

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 to assist in managing their health condition.

What will the advisory group do?

Group members will discuss their experience of using the internet and smartphones 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

If you are interested in being involved and joining the advisory group, or just looking to learn more, please email us on info@sicklecellsociety.org

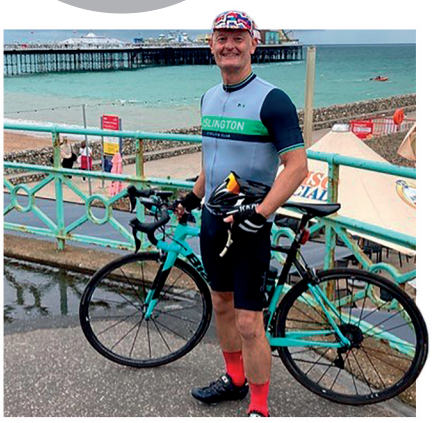
FUNDRAISING SPOTLIGHT

FA massive thank you to Christopher for donating £783 to support our work and for using his platform to raise awareness of sickle cell!

Tolu Adams for raising £539 by walking 12,000 steps a day in March.
Kizzy Constantine for running the virtual London Marathon in April and raising £482.10

Aimee Wood for raising £92 with her Lands End to John o'Groats Virtual Challenge

Huge thank you to Funmi Ogundiran for raising an impressive £1286 by running her own half-marathon to celebrate her 22nd birthday! Happy 22nd Birthday Fumi!! What a way to celebrate!



A massive thank you to everyone at the Islington Cycling Club who raised money for sickle cell with their Fish'n'Chips Ride to Brighton fundraiser in memory of Leroy Hodge. ICC Ride to Brighton. Above: ICC Member Colin Fisher in Brighton after completing the challenge.

Huge thank you to Ciani Vanhorn for completing the Thames Bridge 25km Trek in September raising an impressive £500.

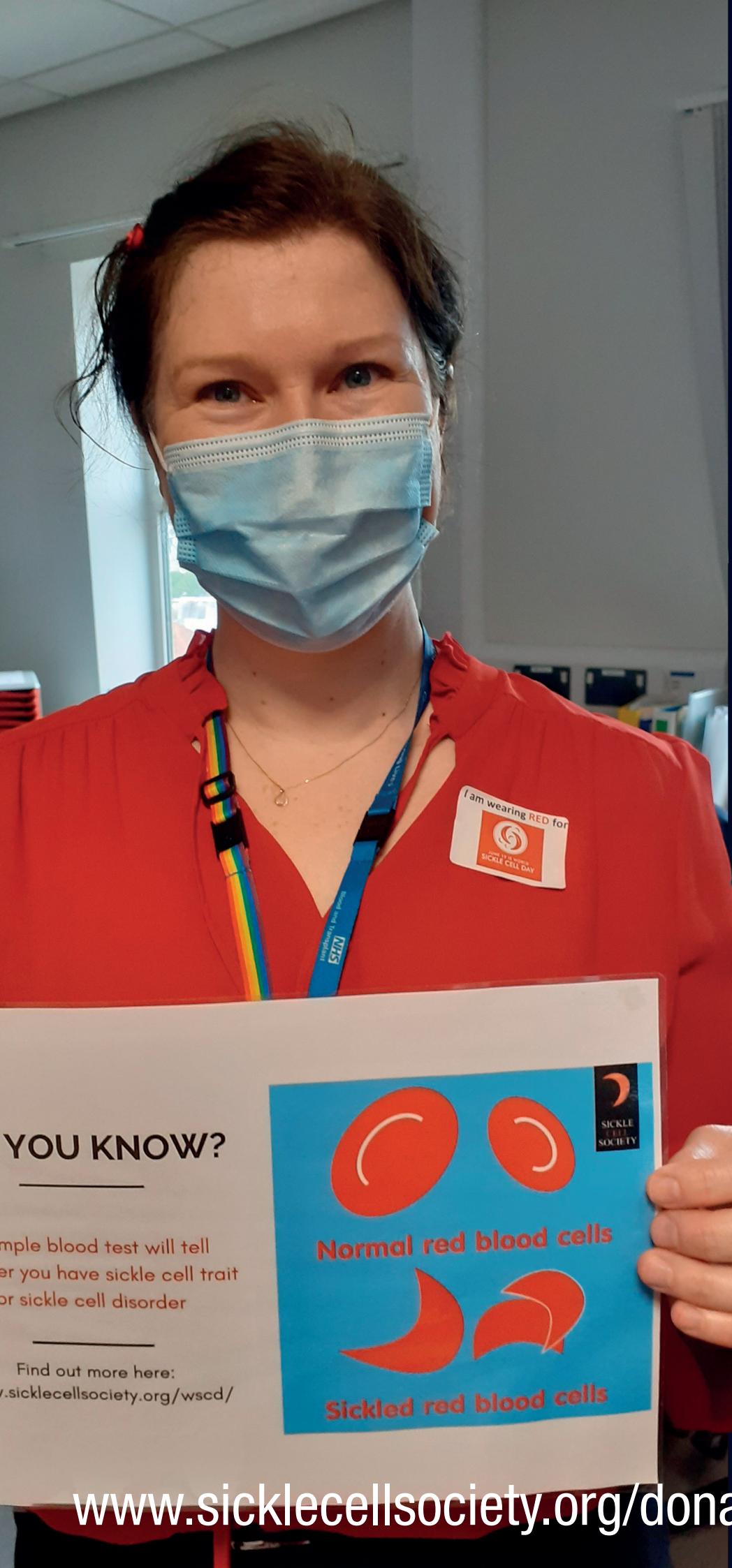
A huge thank you to the former Mayor of Brent, Councillor Ernest Ezeajughi, who during his time as Mayor has raised over £24,000 to support our work

A big thank you to Alan Hovell and the team for a fantastic guided tour of Harlesden and for raising money to support our work

Dreams From My Mother

Dreams From My Mother is the inspirational life story of Dame Elizabeth Anionwu, one of our founders and patrons, who spent her career fighting racial injustice and becoming the first ever sickle cell nurse specialist, and recently brought to the nation's attention how Covid-19 has had a devastating effect on Black and Asian communities. But behind all of her incredible accomplishments is an incredibly moving story of a mother and a daughter separated by society, but united in the dreams they shared for her future.

A massive congratulations to Dame Elizabeth for publishing another book, we look forward to reading it!



SICKLE CELL SOCIETY

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

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

www.sicklecellsociety.org/donate