sickle cell

SICKLE CELL SOCIETY

THE NEWSLETTER OF THE SICKLE CELL SOCIETY

SUMMER 2024

In this issue:

www.sicklecellsociety.org

Contents

Sickle Cell Society Newsletter Summer 2024

Editor Paula Shutt
Sickle Cell Society 54 Station Road London NW10 4UA
T. 020 8963 7798
E. communications@sicklecellsociety.org

What's New?

It's been a while since our last update, but we're working on getting back to a regular newsletter schedule. In the meantime, here's a quick overview of what's new:

NHS Response to "No-One's Listening" Report:
Since the release of our report, the NHS has initiated a review of sickle cell care. We're beginning to see new services designed to improve the care for people with sickle cell. More details on pages 6-8.

Superpowers and Sickle Cell:
This summer, it's been amazing to see the conversation around sickle cell gain so much attention. We've been thrilled to collaborate with Netflix on their Number One show, Supacell, which brought superpowers and sickle cell disorder into the spotlight. More on page 4.

New Legal Support via Our Helpline:
We're now offering legal assistance through our helpline to support those affected by sickle cell. See page 9.

Upcoming Sickle Cell Treatment Decision:
We're eagerly awaiting the decision on whether the new sickle cell treatment we've been campaigning for will be approved for use in the NHS. See page 9

New Medical Trial at King's College London:
A new trial is underway, exploring haplo-identical stem cell transplants for adults with sickle cell disorder – where the donor is a 50% match, such as a sibling. The study could potentially gather research to support haplo transplants on the NHS. More information on page 18.

What else is new?
We're expanding the Children and Young People's Peer Mentoring Programme, which offers crucial support to young people with sickle cell. Currently available in London, we're now extending it to the North West and Sheffield. We'll keep you updated as the project develops.

John James OBE

RAISING AWARENESS

Netflix Supacell

In this year's World Sickle Cell Day theme on 19 June, we emphasised the importance of being "better together" within the sickle cell community. Whether it's leaning on a supportive circle of friends, family, healthcare professionals, or related organisations, having that network is crucial when living with the condition.

In addition to collaborating with people living with the condition to strengthen our messages to decision-makers, we also partner with other organisations to amplify awareness about sickle cell. Our recent collaboration with Netflix on the show 'Supacell' has created a significant buzz worldwide, sparking important conversations about sickle cell in the media and among the general public, and emphasising the importance of a supportive community for living life to the full with sickle cell.

Supacell premiered on Netflix in June and follows a group of people who discover they have superpowers. Without giving too much away, the show weaves in themes related to sickle cell trait and disorder, which certainly got people talking. Online mentions of sickle cell surged over the summer, at the same rate as discussions about Supacell—showing just how powerful popular media can be in raising awareness.

We've been thrilled with Netflix's commitment to raising the profile of sickle cell, especially as the show topped the Netflix charts. Rapman, the creator, director, and writer of Supacell, shared his thoughts exclusively with ABC News Australia:

'I'm so proud of the impact that Supacell has had since launching back in June. Supacell was number one in the world, watched by millions and started an important conversation about sickle cell, encouraging people to learn more and speak about some of their own experiences. I'm still getting messages from young people and parents about how they now feel empowered to talk about it with their friends. I've always tried to authentically reflect the lives of Black people in my stories, so it's exciting that Supacell will return to Netflix for a second season.'

The show's discussion of both sickle cell trait and disorder has been a valuable opportunity for us to also talk more about what sickle cell trait means to different people.

Living with sickle cell often means having difficult conversations, and we hope to support you in that through our materials, the content we share, our media interviews, podcasts, and our work with Netflix. We hope you find these resources helpful, and we'd love to hear how they've supported you. Please email us at communications@sicklecellsociety.org

Sickle Cell Awareness Month

September marks a month of awareness raising about sickle cell, and we have lots

Podcast host and panel – episode 1: transition to adult sickle cell care

going on. Our staff and volunteers will be out and about at events all month long, spreading the word across the country about blood donation. We'll also be online, discussing what sickle cell is, sharing tips on nutrition and exercise, addressing mental health, and updating you on the latest changes in sickle cell care.

In the coming months, we'll be sharing more about what's new at the Society, including the expansion of our successful mentoring programme across London, and to Liverpool, Manchester, and Sheffield. We're also excited about our work with Genomics England and the James Lind Alliance as we look toward the future of sickle cell research.

In June, on World Sickle Cell Day, we launched our podcast with a focus on the transition from child to adult sickle cell services. The episode featured a panel of child and adult haematologists, a clinical psychologist, and two patients – who shared valuable tips for anyone going through this experience. The podcast is available on our YouTube channel, website, Apple Podcasts, Spotify, and other platforms.

SICKLE CELL CARE AND THE NHS

We can't talk about sickle cell care in the NHS without first reflecting on why we founded this Charity and why we published the 'No One's Listening' report in 2021.

For years, we have faced numerous challenges, including racial bias, underinvestment, and a lack of research into sickle cell disorder. However, since the release of the No One's Listening report, there has been a renewed focus on improving sickle cell care within the NHS. We've seen increased investment and resources directed towards making improvements in care, and while there's still progress to be made, we're beginning to see positive change.

Our Patron, Dame Elizabeth Anionwu, and our Chief Executive, John James

Our goal is to highlight the advancements being made so that you can see the impact of your stories, feedback, case studies, and continued involvement in our campaigning efforts.

Your engagement in campaigning for these changes has proved crucial, as it has provided healthcare professionals with the necessary feedback to assess how changes are benefiting the sickle cell community. Your feedback will continue to be essential in identifying what's working well and where further improvements are needed.

NHS Improvements in sickle cell care

Improvements are being rolled out across areas and hospitals, so if you're not aware of them, ask your healthcare team if any of these new developments are available in your area:

Patient Cards

Sickle Cell Patient Cards are being rolled out to patients, to show to ambulance staff and/or in A&E departments... if you access hospital care in England during a crisis. The card helps to explain that you are a sickle cell patient and have a right to pain relief within 30 minutes of arrival. At the time of writing, we are working with NHS England on ensuring people who want the card can access one.

Digital Care Plans

Every patient with sickle cell will have access to a digital care plan to ensure they get personalised care, wherever they access care in England. This might be of particular benefit if you are away from home, and need sickle cell care at a hospital you have never visited before.

Iyamide Thomas and our Chair Michele Salter promote the latest on antenatal sickle cell screening, a programme we successfully lobbied for

Hyper Acute Units

Progress has begun on seven new sickle cell emergency bypass units where sickle cell patients can receive 24/7 specialist support, emergency care and rapid pain relief. This will allow more patients to avoid waiting in A&E for emergency treatment and faster access to sickle cell specialists. The first one opened in Manchester earlier this year, and others are being rolled out across the country.

"ACT NOW" Sickle Cell acronym in A&E units

The ACT NOW acronym has been developed collaboratively with clinical experts and patients and supports a rapid and effective response to a sickle cell crisis. The acronym is being used in Emergency Departments, bypass units, relevant acute wards, London Ambulance Service and the Prison Service. The project is measuring how useful it is to use an acronym: 'ACT NOW' for staff to quickly access information about the steps they should go through if someone arrives in a sickle cell crisis.

For example, the 'A' in ACT NOW stands for 'analgesia', and gives the clinician the guideline that they should be administering pain relief to you within 30 minutes of your arrival. If you see posters promoting the acronym in a hospital, please ask about the pilot.

Celebrating Success

We look back at last year, where The Duke and Duchess of Edinburgh were joined by a remarkable assembly of 1,500 healthcare professionals, politicians, and NHS supporters at a special ceremony to mark the NHS's 75th anniversary.

The service, held at Westminster Abbey in July, paid tribute to NHS staff and patients, and was attended by our own Chief Executive, John James, and our Patron, Dame Elizabeth Anionwu.

HM King Charles III and HM Queen Camilla

The ceremony was enriched with prayers and testimonials from prominent health leaders, and attendees included porters and volunteers, along with individuals who demonstrated exceptional bravery on the frontline.

It was fitting to have sickle cell represented, as the history of the condition, and of the Sickle Cell Society, is woven into the story of the NHS.

Sickle Cell and the NHS

The 'Windrush generation' was named after the ship that brought the first large group of Caribbean immigrants to the UK in 1948, and subsequent groups of Caribbean people arriving in the UK until the 1970s. This was at the invitation of the British government, who needed willing workers to fill a

serious labour shortage and provide the fledgling NHS with nursing and other staff.

These individuals made substantial contributions to various sectors, including healthcare, education, and public services. They enriched the cultural fabric of the nation, leaving an indelible mark on British society.

Many individuals from the Windrush generation and subsequent generations carry the sickle cell trait or live with the disease. So, while the sickle cell community has grown and has been reliant on the NHS, the NHS itself has been growing and developing through the valuable input of that same community of people.

Progress

There is much more to be done when it comes to sickle cell and the NHS, but we can take time to look back and see the progress we've made over the years.

We are proud that it was the Sickle Cell Society who campaigned successfully, in collaboration with healthcare professionals, to secure a new NHS policy for funding of adult bone marrow and stem cell transplants. Prior to that milestone of success, the NHS would only fund bone marrow and stem cell transplants for children with a sibling donor.

The Sickle Cell Society was also part of the lobby for a screening programme in England, resulting in the implementation of the Sickle Cell and Thalassaemia Screening Programme – which offers antenatal and newborn testing for the condition. The programme is now used as a model for other screening programmes across the world.

The launch of the No-One's Listening report was also a pivotal moment in our Sickle Cell and NHS history – this is a story that is still unfolding, and showing positive signs of progress to levels never reached before. It fuels our hopes for a more equal future where people with sickle cell always get the quality medical care they need and deserve.

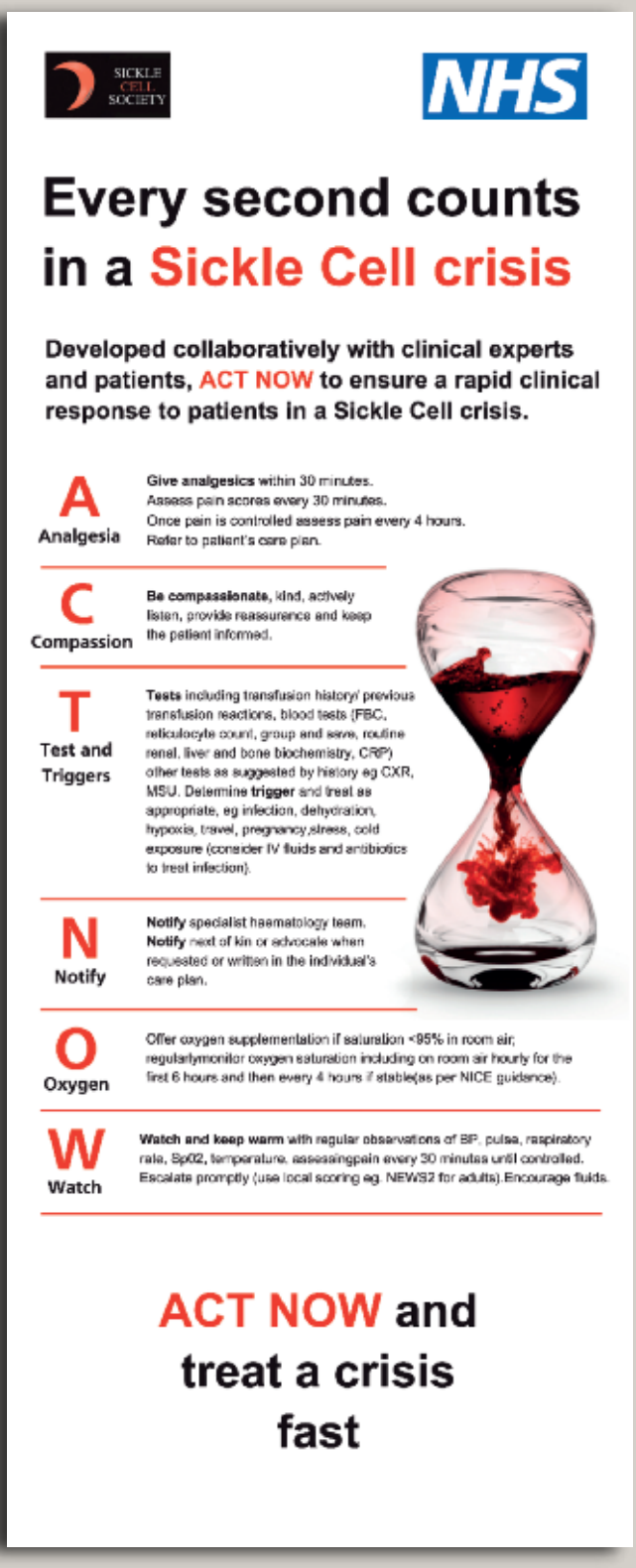
There are so many more great stories of strength of human spirit and progress in the sickle cell community, in community groups and from individuals.

So, there has been much to celebrate! Given the huge challenge we faced when we began this charity in the 1970s, we're proud of the part that we as a Society, and the entirety of the sickle cell community, has taken in making progress with sickle cell healthcare over that time.

"It was a privilege to attend the service at Westminster Abbey," said John James, "where the spotlight shone on sickle cell awareness during the opening speech delivered by our Patron, Dame Professor Elizabeth Anionwu.

While she shared her experiences as a sickle cell nurse, it was very special to witness the significance of that moment, as the historic Abbey's arches amplified and echoed our important messages to the distinguished and influential audience of royalty, the Prime Minister, and many other leaders.

We extend our heartfelt congratulations to the NHS and all the dedicated staff who have had an unwavering commitment to providing quality care over the past 75 years. We also commend their current efforts to enhance sickle cell care and to make meaningful improvements in this crucial aspect of healthcare."



Sickle cell treatment news

This year has seen notable progress in the development of new treatments for sickle cell disorder.

Voxelotor

In May 2024, the National Institute for Health and Care Excellence (NICE) recommended Voxelotor (Oxbryta®) for use in the NHS to treat sickle cell anaemia in individuals aged 12 and older. The drug, which is administered as a once-daily tablet, was immediately made available on the NHS. Voxelotor has the potential to reduce the need for blood transfusions and decrease the number of hospital appointments for patients.

Following its introduction in England, Voxelotor was also approved for restricted use in Scotland. The restriction means it is available as a second-line treatment for patients who cannot take hydroxycarbamide or for whom it has been ineffective.

Casgevy

The Medicines and Healthcare products Regulatory Agency (MHRA) has approved Casgevy, a groundbreaking gene therapy for people with sickle cell disorder. The final approval required before it can be offered to patients by the NHS is currently under review by NICE. This life-changing therapy involves removing and replacing the gene responsible for sickle cell, effectively offering a cure for the condition.

We eagerly await NICE's final decision and will share the outcome widely once it has been announced.

Blood Matching for Transfusions

In January, the NHS became the first healthcare system in the world to introduce a new blood group genotyping test, aimed at transforming care for patients living with sickle cell disorder and thalassaemia.

This genetic test enables more precise matching of blood transfusions, reducing the risk of side effects and providing more personalised care. The DNA analysis of a patient's blood groups allows for more accurate matching for those who need transfusions, helping to identify the best compatible blood for patients with complex requirements. Some donor blood is also being tested in a parallel programme.

Haemoglobinopathy Nurses can offer extended blood group testing to people with sickle cell. Patients can give a blood sample at a routine appointment to enable the DNA-based testing of extended blood groups. Look out for posters and information to see if it is being offered near you.

Legal Support

The Helpline team is now collaborating with a local law centre to provide specialised support for those affected by Sickle Cell & Thalassaemia in South-East London. This service, available exclusively through referrals from the Sickle Cell Society, is designed to assist patients, families, and carers living in or receiving care within the South-East London area.

The law centre specialises in Welfare Rights, particularly legal matters related to benefits. They handle cases such as:

- Representation at First-tier and Upper Tribunal for unfavourable benefit decisions.
- Challenges to local authorities regarding benefits.

Please note, they are unable to assist with making initial claims or maintaining existing claims.

If you or someone you know with sickle cell meets these criteria and needs support with housing issues, DLA, PIP, or other welfare matters, please contact us. We will assess the situation and, if appropriate, refer the case to the Law Centre.

Helpline: opening hours are : Mon – Fri 9m – 5pm (except bank holidays)
T: Mon & Tue: 07842 245 980; Wed: 020 89617795; Thurs & Fri: 07809736089
info@sicklecellsociety.org

Leaving a Gift

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

17,500 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/
or by calling our
Fundraising Officer on 020 8963 7793
Thank you, we greatly appreciate your support.

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**

Black Unity Bike Ride

Support from the sickle cell community is truly remarkable. Let's reflect on an incredible event which celebrated black health whilst also paying tribute to a dedicated warrior who tirelessly championed our cause. A further positive: it served as a platform to encourage new black heritage blood donors to contribute.

Both our Chief Executive and Trustee Board Chair actively participated in the Black Unity Bike Ride, an important initiative striving to boost black community participation in physical activity, while prioritising overall health and wellbeing.

We worked with the Black Unity Bike Ride to increase black heritage blood donations and speak to participants about our work on the 'Give Blood, Spread Love' (GBSL) project. The increased demand for some rare blood subtypes, such as Ro – more common in people of Black or mixed heritage – means we need more black and mixed race people to become blood donors; our GBSL programme works in the community to increase donation levels.

Despite facing rain on the day, the event was a resounding success, and our heartfelt gratitude goes out to everyone involved.

Photos: Roberts and Josh Gordon

This gathering held special significance as it was dedicated in part to the memory of Dionne Farley, a passionate sickle cell warrior and one of our staunch supporters. Dionne, who passed in April 2023, played a significant role in advocating for our cause and rallying others to support us. Many of us at the Society had the privilege of knowing Dionne, and she was beloved within the black cycling community in London. Her absence is deeply felt, and she is truly missed.

One person's trash is another person's treasure

Loose coins found in household waste got a second life after they were donated to us at the Sickle Cell Society thanks to Veolia Southwark, providers of recycling and waste services for Southwark Council.

There are countless ways to raise money to support charity, but few are as unique as this. Lucian Lodge, one of Veolia Southwark's traffic marshalls, has been collecting lost change from the recycling facility floor for the past five years. With no way to reunite the coins with their original owners, Lucian instead donates them to charity. Dedicated to the cause, Lucian has been coming into work half an hour early every shift since 2019 to retrieve any loose coins accidentally ending up at the recycling facility.

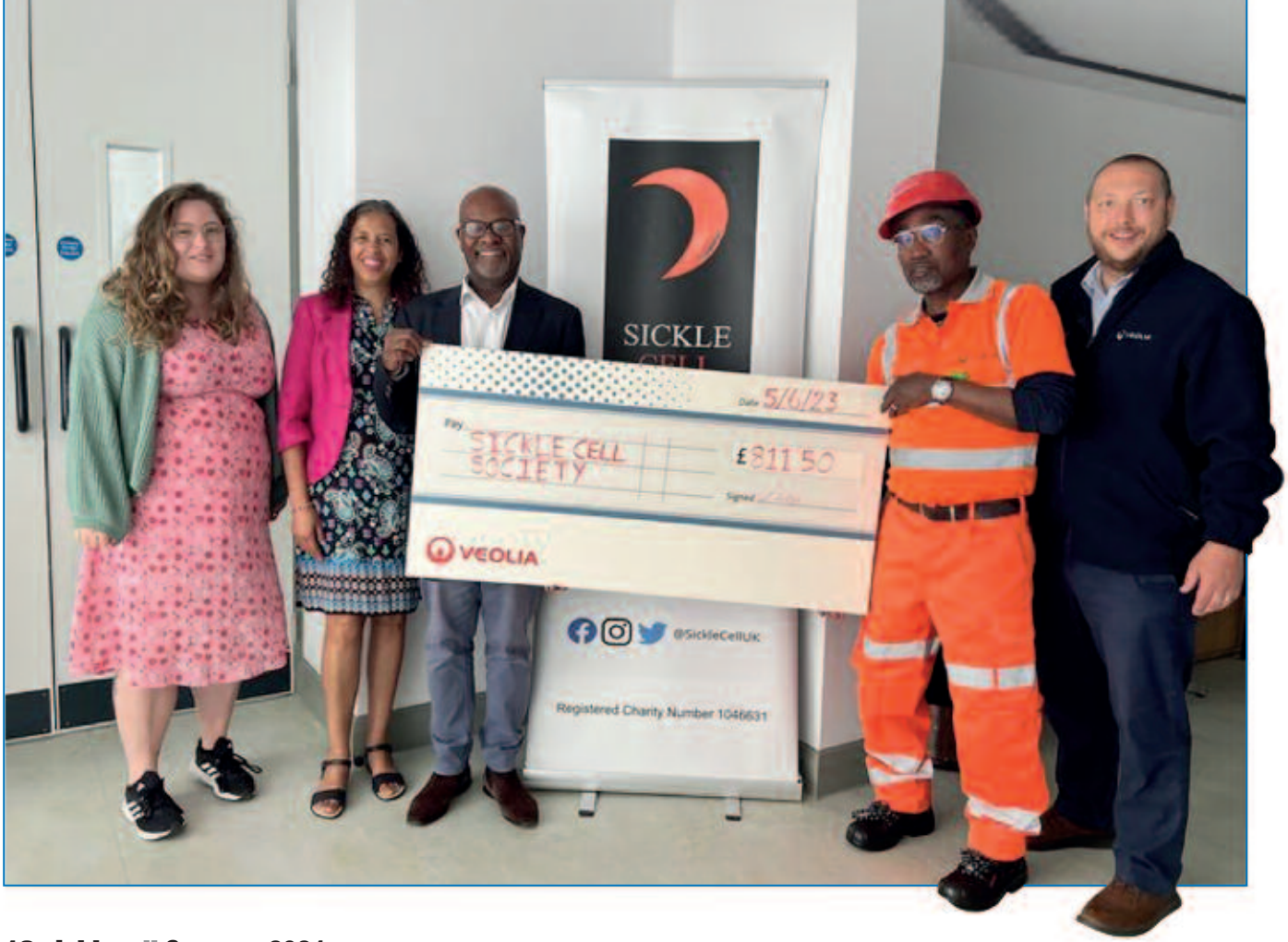
Over the past eighteen months since his previous donation, he has collected £811 – over £160 more than his last collection. To celebrate this fantastic donation, Lucian came to our office to meet the team.

After the recycling is collected from homes across London, it is sorted into different materials. These materials are pressurised into condensed bales and sent off to be made into new products. However, in this baling process, small pieces of metal, including coins, often slip through the cracks. This is where Lucian found the change he collected, so even those pieces that don't make it through get recycled.

"It all started in 2019 when I discovered 1ps, 2ps, 5ps and 10ps hidden in the waste," says Lucian. "My manager agreed
I could take out whatever I could find and give to charity. Since that day, I've been coming into work early every day to collect coins. My target is three to four pounds a day. I put my time into doing this because I see what my son goes through with the sickness."

SCS Chief Executive, John James, voiced his gratitude on behalf of the society: "We want to say a big thank you to Lucian and the entire team at Veolia for fundraising in such an innovative way. This donation will go towards the vital work we do supporting people living with Sickle Cell Disorder and their families."

Interested in fundraising for our work? Find out how at
www.sicklecellsociety.org/fundraising



Online Shopping

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

Online shopping is a convenient way to shop, particularly if you're avoiding crowded high streets.

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

Throughout September if you buy anything at the Miffy online shop : miffy.co.uk , 20% of the cost will be donated to us.

Helpline

Our 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

5 days a week from 9am to 5pm (except bank holidays) Before calling please see the correct number to call for each day of the week:

Mon & Tue: **M:** 07842 245 980;
Wed: **T:** 0208 961 7795;
Thurs & Fri: **M:** 07809 736 089
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.
You can also use our confidential email service:
info@sicklecellsociety.org

Iron Overload in sickle cell disorder

People with sickle cell disorder may have a lifelong reliance on blood transfusions – an important part of treatment for the condition. Regular blood transfusions are used to reduce the likelihood of clotting and therefore stroke. Blood transfusions are also used on occasion to help treat other complications of SCD such as acute chest syndrome, acute anaemia, or acute priapism.

Over time, though, this may lead to complications, such as iron overload.

How do blood transfusions cause iron overload?

In a person who does not have blood transfusions, iron levels are balanced through the body's own controls on the way we absorb iron from the food we eat. The body has no natural mechanism to rid itself of iron, which is why additional iron from blood transfusions is stored in the liver, the primary iron storage site.

Why is iron overload problematic?

Iron is an essential element for blood production, so having extra iron in the body sounds like it might be a good thing.

In fact, increased liver iron is toxic. If not managed, it can lead to fibrosis,

cirrhosis and a higher risk of developing liver cancer. In a study of 141 deaths of SCD patients between 1976 and 2001, iron overload was found to be present in about a third of patients, with 7% of the deaths directly linked to iron overload.

Patients at risk of iron overload are treated with iron-removing medicine: drugs called 'chelators'. Iron chelators *work by binding to the extra iron so that it can be removed from the body* through urine and/or faeces.

How is iron overload diagnosed?

A protein called ferritin stores iron *inside your cells.* It allows your body to use the iron when it needs it. The amount of ferritin in the blood (serum ferritin level) is related to the amount of iron stored in your body. Measuring 'serum ferritin' is used to find out if there is too much iron in the body. It helps predict overall trends; however, its ability to accurately tell if there is too much liver iron is limited.

In the past, biopsy was used to measure the quantity of iron in the liver. This is a medical procedure where a small sample of tissue is taken for examination. Nowadays, this invasive procedure is no longer required to accurately measure liver iron. Instead, magnetic resonance imaging (MRI) is used as a non-invasive, pain-free alternative to measure liver iron concentration (LIC).

There are different MRI methods available. In the UK, FerriScan is the most commonly used method to measure iron overload in sickle cell patients.

How does a liver MRI work?

Depending on the MRI method used, the patient spends about 10-15 minutes in the MRI scanner. The MRI images are then used to measure the patient's liver iron concentration (LIC) either by a radiologist analysing the images, by specialist external providers, or through automatic analysis such as 'FerriSmart'. The resulting LIC report then helps doctors to make decisions about any adjustments that need to be made to iron chelator drug dosages.

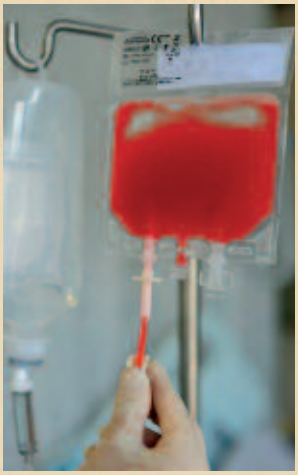
A liver MRI test is often carried out annually when a patient has continuous blood transfusions, and the need for iron chelation therapy.

Why do liver MRIs matter for iron chelation therapy?

Iron chelation therapy reduces the risk of organ damage from iron overload. It reduces tissue iron to a level at which damage no longer occurs.

Measurement of liver iron concentration helps doctors to make decisions about when chelation therapy should be started, whether the chelator dose should be increased or decreased, and when chelation therapy should be stopped. In this way, tissue iron can be maintained at safe levels while minimising the risks of chelator toxicity.

Getting help



Iron overload is a complication of blood transfusions over time for sickle cell patients.

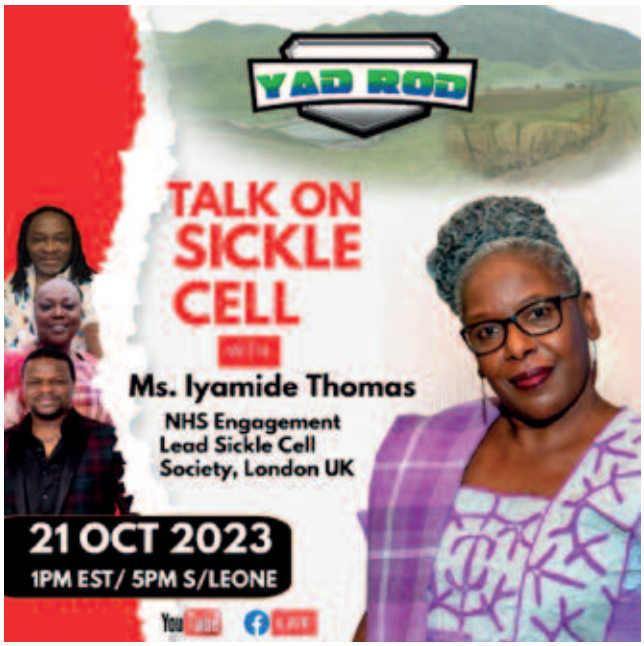
However, blood transfusions are still an important therapy, and very much relied upon by many people living with the condition. Our *Give Blood Spread Love* programme aims to increase the numbers of donors, and we encourage people with black and mixed race heritage to give blood.

If you have any questions about iron overload, or treatments for iron overload, please speak to your nurse or consultant, or reach out to our helpline info@sicklecellsociety.org

MRI measurement of Liver Iron Concentration

Update on the Sickle Cell and Thalassaemia Screening 'Engagement Project'

Iyamide Thomas
NHS Engagement Lead (Screening Programme)



The Engagement Project that we run jointly with the UK Thalassaemia Society (UKTS) works with the antenatal and newborn screening programme for sickle cell disorder and thalassaemia. The project ensures that the NHS Sickle Cell and Thalassaemia Screening Programme is underpinned by service user needs and addresses any inequalities.

We are pleased to announce that, after an application process, and along with UKTS we were successful in securing the new NHS Sickle Cell and Thalassaemia Screening (SCT) Programme contract in the autumn. This is good news and once again allows us to continue building on the good work we've already done over the years. Below is an update on the project.

'It's in Our Genes'

'It's in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia' was the report we launched at a conference in April last year (www.sicklecellsociety.org/resource/its-in-our-genes/). It was based on service user focus groups conducted to gain feedback on people's experiences of sickle cell and thalassaemia screening. The aims were to use the feedback to help influence future screening policy. Some of the feedback and recommendations have now been incorporated into the forthcoming NHS SCT Screening Programme resource for healthcare professionals- *'Protocol for Reporting newborn screening results for sickle cell disease and thalassaemia major to parents'* due out shortly.

The conference in April was recorded and the various presentations are on our YouTube channel, under 'playlists'.

The *'It's in Our Genes*' report is being well received and at the London Maternity and Midwifery Festival 2024, along with UKTS, we co-presented the work on the focus groups at their event, which was attended by over 500 participants. Another abstract was accepted by Brighton and Sussex Medical School's Anti-racism in Healthcare conference and we presented a poster there earlier this year.

Outreach

Outreach is a continuous work-stream of the project and along with UKTS, we use our pooled networks to raise awareness to the public and health professionals on screening issues, as well as general awareness of sickle cell and thalassaemia.

We mainly do this via talks, events and social media. During the pandemic, a lot of our outreach was successfully conducted online. We now do both in-person and online outreach, such as the YouTube interview and Q&A for Black History Month for 'YAD ROD', a USA based media group that targets mainly the Sierra Leonean and West African Diaspora. They conduct their discussions in 'Krio' which is Sierra Leone's lingua franca and is a type of 'patois'. The session had just over 100 live views and to date has been viewed 494 times. You can find the event on the YAD ROD YouTube channel and try out your understanding of Krio!

Another key outreach event for Black History Month was a talk to staff at Coca Cola Europacific Partners HQ.

This talk was in-person and recorded for staff internationally to view online. For the first time in the

Iyamide (Left) with staff at Coca Cola who organised a Black History Month awareness event

BHM cakes and QR Codes for donations

discussion afterwards, two female sickle cell 'carriers' (i.e. trait) reported their experiences of deep sea-diving and mountain climbing. These are two situations where advice would generally be for carriers to be cautious, as sickling can occur. The hosts then treated us to some customised Black History Month cupcakes and a tasty Black History Month lunch menu. We would like to say a big thank-you to staff at Coca-Cola for the generous donation made.

We also gave awareness talks to staff at AVIVA and to Wells Fargo Investment Bank**.** Our Engagement Lead, Iyamide Thomas also wrote an article in African Voice newspaper which particularly raised awareness of screening and the *'It's in Our Genes'* report. To date this article has been viewed over 1500 times.

Additional outreach by colleagues helped raise awareness of screening at the Notting Hill Carnival and the Mayor of London's 'Black on the Square' event at Trafalgar Square.

New Sickle Cell Leaflet

We have updated our Sickle Cell Society leaflet on *'Sickle Cell Disorder and Sickle Cell Trait'* and it now includes a page on screening and preconception testing.

International e-Learning Resource

As part of a Great Ormond St Hospital project we're working on a resource for health professionals, in the UK, Africa and the Caribbean. In collaboration with two sickle cell nurse experts we'll produce a chapter on community care, awareness and social aspects of SCD, including why it's important to get tested. We have also made plans to film service users for the project.

What Next?

Workstreams proposed include focus groups with health professionals, preconception outreach and horizon scanning of new technologies such as the Genomics England Generation Study.

The Project Advisory group's core objective will be to ensure service user needs are met and that there are no inequalities in service delivery.

For more comprehensive information on the project please see the annual progress reports on our website:
www.sicklecellsociety.org/screeningprogramme/

CLINICAL TRIALS : REDRESS STUDY

REDRESS is a sickle cell disorder-related medical study which launched last year, with its first site at King's College Hospital, London. It was set up to investigate the use of stem cell transplants in treating people with severe sickle cell disease and aims to enrol 120 participants from NHS sites across the UK.

Given the limited options for standard treatment of sickle cell, stem cell transplant is a promising procedure, but the need to find a perfect stem cell donor match has added a layer of challenge. The process takes stem cells from a compatible donor and administers them to people with sickle cell, which enables healthy red blood cells to be produced instead of sickle shaped cells.

While stem cell transplant offers high cure rates when recipients have a 100% matched sibling, this opportunity is not available to everyone. Almost 3/4 of patients do not have a relative with a 100% match.

Another option is stem cell transplant from relatives who are a 50% match, known as haplo-identical (haplo) stem cell transplant. This is available to children under the age of 18 with sickle cell disorder in England, and research shows it is safe and effective in that age group.

To prove it is also safe and effective for adults, more research is needed. Initially, there were concerns that haplo stem cell transplant would not work because it would cause high rejection rates. However, recent research and updated protocols now allow haplo stem cell transplant to be performed successfully in adults with severe sickle cell disorder.

REDRESS represents an opportunity to gather research to potentially support haplo transplants for adults on the NHS. It is a clinical trial comparing haplo stem cell transplant to standard care, and seeks to address this gap in knowledge.

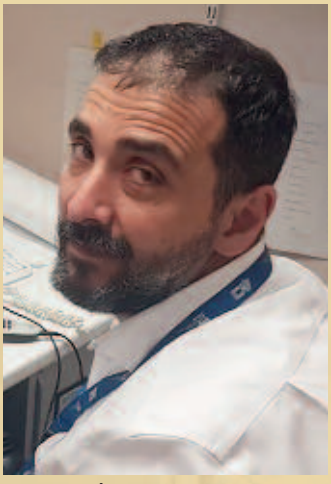
Photo: rocketclips

Stem cell transplant is an expensive treatment, so through the trial there is a chance to show that it provides good value for money and improves the quality of life for patients compared to the usual (standard) treatments for sickle cell disorder.

For more information on REDRESS, please visit the website at www.redresstrial.co.uk or contact the study team via email at redress@kcl.ac.uk.

In Memory of Dr Dimitris Tsitsikas

Head Haematology Consultant Homerton University Hospital NHS Foundation Trust



Like many of you we were profoundly saddened by the loss of Dr Tsitsikas, and understandably we are profoundly saddened by this loss. It has been felt far and wide across the globe and will leave a huge space to fill.

Dr Tsitsikas believed in social equality, coffee, and data on everything! These literally translated into his everyday practice. He always went above and beyond for the patients, and they felt listened to and seen. He even managed to get the patients interested and excited about research and clinical trials! Continuously dedicated to improving patient outcomes he was exploring a research study in Therapeutic Plasma Exchange in sickle cell disease. Which is something we as a team will take forward in his memory. The results from this procedure have seen a significant improvement in patient outcomes improving life expectancy by 80%.

Dr Tsitsikas not only had a brilliant mind, but he was also creative and found innovative ways to engage with patients to get information to them when they needed it most. He created videos, web talks and more always acting as a patient advocate and challenging perceptions. He was funny, had a very dry sense of humour and took care of all those around him, especially his team. He respected and valued everyone's contribution, encouraged academic development, and ensured all those around him participated in the creation of peer-reviewed scientific papers with the aim to improve patient outcomes.

He will be missed but we will endeavour to keep his legacy and work moving forward.

From from the Team at the Homerton , ourselves at the Sickle Cell Society and the many patients and healthcare professional who knew Dimitris.

Young People's Survey

Are you aged between 13 and 21 and affected by sickle cell in some way? Your voice matters!

We'd love to hear from young people aged between 13 and 21 years old who are affected by sickle cell. Whether you, a family member, or someone you care about lives with sickle cell, we'd really like to hear what you have to say.

Why? Because we'd like to know more about the daily challenges you face and what we, the Sickle Cell Society, can do to support you.

Understanding more about the type of help or support young people growing up with sickle cell needs will help us shape the range of services we offer. We'll be able to offer the right activities, services, advice and support networks so you can make the most of your potential and enjoy your future.

Can you complete this brief survey? It'll just take 5 minutes of your time and the first 50 participants will receive a £15 Amazon voucher as a thank you.

For this purpose only, we will ask for your email address, but we won't use it or share it.

All responses will be anonymous and data collected will be kept confidential – it won't be shared with anyone else.

To take part please scan the QR code.

Section One: About you

How old are you? Please tick one

❏ 13 to 15
❏ 16 to 18
❏ 19 to 21

Who in your family is affected by sickle cell? Tick all that apply

❏ Me
❏ Brother / sister
❏ Parent / carer
❏ Child
❏ Other
❏ Rather not say

Where do you live? Please tick one

❏ England
❏ North East
❏ North West
❏ Yorkshire & Humber
❏ East Midlands
❏ West Midlands
❏ East of England
❏ London
❏ South East
❏ Scotland
❏ Wales

Please state which region

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.....
.....
.....
.....
.....

What is your gender? Please tick one

❏ Male
❏ Female
❏ Non binary/non conforming
❏ Rather not say

Have you taken part in young people's activities with Sickle Cell Society before?

❏ Yes
❏ No

If Yes, what have you taken part in?

❏ Family retreat / holiday weekend
❏ Online young people's activities
❏ Face to Face young people's activities
❏ Mentoring 1:1
❏ Other _____

What did you enjoy / like about the activities you participated in, if anything?

.....
.....
.....
.....

Was there anything you didn't like about the activities you participated in?

.....
.....
.....
.....

On average, how often do you take part in sport or physical activity? E.g. walking, dancing, climbing wall etc. (please circle your answer)

❏ Weekly
❏ Monthly
❏ Occasionally e.g. 3-4 times a year
❏ Never

Would you like opportunities to take part in more physical activity with your peers (i.e. other young people affected by sickle cell)?

❏ Yes
❏ No

Would you like to take part in more opportunities to have your voice heard alongside your peers? (E.g. work with other young people affected by sickle cell to help schools or health professionals understand your needs better)

❏ Yes
❏ No

Feel free to say more if you would like to:

.....
.....
.....
.....
.....

Section Two: As a young person affected by sickle cell we would like to understand more about your needs.

To what extent do you agree or disagree with the following statements?					
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I would like more opportunities to meet and socialise with others affected by sickle cell					
I enjoy meeting other young people					
I would like more opportunities to express myself creatively					
I don't like talking to others about sickle cell					
I would like more opportunities to learn about sex / sexual relationships					
I find coping with sickle cell stressful					
I enjoy activities where I am part of a team					
I enjoy activities where I can take a lead / have a key role to play					
I am worried about my future					
I feel isolated and / or excluded by the effect sickle cell has on me / my family					
I would like to be better at communicating my needs around sickle cell					
I would like to learn skills that will benefit me at school / college / work					

Is there anything else you would like to add?

……

……

I would like to take part in the following type of activities

- ❑ Physical activities e.g. Climbing wall / paintballing / caving
- ❑ Wellbeing activities e.g. yoga / meditation
- ❑ Creating a podcast, blog or other online content
- ❑ Learning more about key life skills e.g. problem solving, critical thinking, communication skills, coping with stress/emotions, relationship skills and/or making connections, self-awareness and empathy/understanding what others think or feel,
- ❑ Helping develop or taking part in cultural festivals/events
- ❑ Environmental Projects e.g. gardening/learning how to grow foods/plants,
- ❑ Opportunities for online chats / interaction with peers
- ❑ Creative activities e.g. art / music / cooking & baking / dance / theatre etc.
- ❑ After-school club / youth club or meeting space
- ❑ Leadership skills training
- ❑ Participating in a Young People's Steering Group to have my voice heard around sickle cell and the activities of The Sickle Cell Society
- ❑ Volunteering through supporting the running of young people's activities for Sickle Cell Society
- ❑ 1-1 mentoring by a person with sickle cell with similar interests to me
- ❑ Group mentoring with others affected by sickle cell (directly or indirectly)
- ❑ Educational workshops on how to live well with sickle cell e.g. diet / health / nutrition
- ❑ Employment and/or career support
- ❑ Learning to use creativity and/or culture to influence others
- ❑ Take part in weekend events / trips with peers and/or family
- ❑ Any other suggestions…

Thank you for taking part in our survey.

We will email you with a link to your Amazon voucher if you are one of our first 50 participants.

Use another device to scan the QR code to take you to the online survey, or use this link: https://forms.office.com/e/RjN8JiJw9u
Alternatively you can print the form and return it to us by post at 54 Station Road, London NH10 4UA

Dela Lloyd – Honouring a legacy

Dela's family with Elaine & John James

Some of the guests at the event

Meet Dela Lloyd, 78, a vibrant soul whose journey from Ghana to the UK for nursing studies unravelled a life marked by determination and resilience. Dela's story began with childhood pains that persisted into adulthood, baffling doctors in Ghana and England.

It was in 1970, at the age of 25 and suffering with unrelenting pain during her psychiatric nursing studies in Woodbridge, Suffolk, that she was referred to Addenbrookes Hospital, Cambridge. She was finally diagnosed with Sickle Cell disorder.

John, Julie, and Elaine

Back then, awareness of Sickle Cell disorder was scarce. A family member informed Dela that whilst listening to the radio he had learnt meetings were about to start in London for those with the condition. It was there she connected with the remarkable Dame Elizabeth Anionwu, a pioneer in sickle cell and thalassemia nursing, and one of our valued Patrons. Dela, alongside her husband

John, continued to champion the cause, both in London and Suffolk, joining forces with Anetta Bradshaw who had established Sickle Cell Suffolk.

Last summer, the group, organised by Elaine Tappin, coordinator of Sickle Cell Suffolk, honoured Dela's legacy as a Sickle Cell warrior in a heartwarming, 'This is Your Life' presentation.

Speakers included Dr. Martin Besser from Addenbrookes Hospital, John James OBE, our Chief Executive, Elaine Tappin, family, and friends. To top it off, there was a surprise video appearance by Dela's longstanding friend, Dame Elizabeth Anionwu. The event was well attended by the local community, family and friends of Dela, those living with the condition, and specialist staff from Addenbrookes.

Delicious food and music by local artists Nero Diamante and the Ipswich Reggae Choir further elevated the day.

Dela's journey highlighted the challenges many people living with the condition have had, and also the strength of spirit we see time and time again in the sickle cell community across the nation. We are delighted that Dela has been honoured by her peers and we were privileged to have been invited.

The day also saw John James launch Sickle Cell Suffolk's 'Our Blood Saves Lives' campaign. This is part of the national campaign to raise awareness of the need for blood donation from the African and Caribbean community.

To find out more about the project, visit www.sicklecellsuffolk.org/ourbloodsaveslives

Dela and Elaine embrace

Basil Nigel Bramble

Born In 1958: My Milestone

Basil Bramble receiving his Certificate from Angela Smith Chief Executive Officer The Friend's Of Moorfields Eye Hospital

After doing my first article for the Sickle Cell Society a few years ago, 'Basil Bramble: Living with Sickle Cell', I wanted to update readers with my progression as a person living with this blood disorder.

I have eye problems, kidney problems, heart problems, liver problems and so on, so I'm back and forth to the hospital nearly every other week. Living with Sickle Cell means you have so much going on with so many parts of your body, it can be very challenging most weeks, and sometimes I have to head up to hospital for appointments with different consultants in the same week.

I can tell you more, but if you know someone with a chronic illness, you know what they are dealing with and what they are going through. I have to try and live the best I can and get on with it the best I can, taking each day as it comes.

The reason I'm writing this is to let you know I volunteered in March 2023 for Moorfields Eye Hospital (the new Hub in Stratford London), and three days after that I was out clubbing, raving, or partying – whatever you wish to call it – returning home at 05.30am Sunday morning. Life can be so varied, and I had a strong cause for celebration.

Two days after that – 04th April 2023 – I turned sixty-five, which was a big milestone for me.

My father, sister, brothers, cousins and friends gave me some kind words that made me feel great. They have all seen me suffer with this dreadful blood disorder but they have kept me strong.

Yes, I feel proud to reach this age, and yes, it shows you can go through life with so many challenges but still pull through and enjoy living it to the full.

Basil Bramble

Our Give Blood Spread Love team will be travelling around University Fresher's Weeks and other events in September and October, talking about blood donation, and supporting the NHS blood donation campaign for sickle cell awareness month.
On average, every year, 100 blood donors are needed to help each person affected by sickle cell.
Black African and Black Caribbean ethnicity donors are more likely to have the rare sub-type needed to help people with the condition.
Share the blood donation register sign up link in your networks : bit.ly/scsgiveblood and follow our Give Blood Spread Love social pages for updates : Instagram @givebloodspreadlove and X @givebloodlove

SICKLE CELL SOCIETY

The Sickle Cell Society is the only national charity in the UK that supports and represents people affected by a sickle cell disorder to improve their overall quality of life. First set up as a registered charity in 1979, the Sickle Cell Society has been working alongside health care professionals, parents, and people living with sickle cell to raise awareness of the disorder. The Society's aim is to support those living with sickle cell, empowering them to achieve their full potential. We aim to raise awareness of sickle cell disorders, push for improvements to treatment and provide advice, information and support to the sickle cell community. We produce information resources about sickle cell disorders and hold education and awareness events. We provide a helpline service as well as an annual children's holiday and children's activities to provide a respite break for children with sickle cell disorders and their families. We undertake lobbying work to draw attention to issues affecting the sickle cell community

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

www.sicklecellsociety.org/donate