sickle cell

SICKLE CELL SOCIETY

THE NEWSLETTER OF THE SICKLE CELL SOCIETY

SUMMER 2023

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and much more...

www.sicklecellsociety.org

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From our CEO

Time flies when you're having fun and it's definitely been flying by at the Sickle Cell Society as we have been juggling the multitude of projects which raise awareness of Sickle Cell, engage with those in the Sickle Cell Community and support research into treatments.

I would like to extend a warm welcome to Claudette Allerdyce who joins us as a trustee and to Paula Shutt, our new Comms Manager.

This issue includes an interesting article on Healthcare and Race by Artvocate. We also have featured on tips for University Students living with Sickle Cell and a "real life" blog from Victoria Sajowa on Sickle Cell and Doctorhood.

There is much progress to celebrate when it comes to improvements in research, care and support for people living with Sickle Cell and indeed, Celebrating Progress was our theme for World Sickle Cell Day recently.

World Sickle Cell Day also saw the launch of our Priapism awareness campaign in conjunction with Guys and St Thomas's hospital and Boston Scientific which you can read more about in this issue.

In addition, we also have the usual inclusions from our Screening Engagement, Fundraising and Mentoring teams.

As always, a reminder that help and support for people living with sickle cell is available via our website and our helpline remains available 5 days a week from 10 am – 5 pm.

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

John James OBE Chief Executive

Percy Lane Memorial Award

We are thrilled to announce that our CEO John James OBE has won the Percy Lane Oliver Memorial Award 2022 (Lay Category), for his outstanding contribution to blood and transfusion science.

The Percy Lane Oliver Memorial Award, awarded by the Royal College of Pathologists was established in 1944, following the death of Percy Lane Oliver, the creator of the world's first voluntary blood donor service in 1921. The award gives public recognition to professional and lay people who have made an outstanding contribution to the Science, Practice or Administration of Blood Transfusion.

On winning the award, John said "I am extremely humbled to be a recipient of the 2022 Percy Lane Oliver Memorial Award. Having spent my working life in the public sector and third sector organisations, I am extremely passionate about the difference which vital Blood Transfusions make to those who need them. I will continue to campaign for more Blood donors, especially for more donors from the Black community. Thank You for the award."

Claudette Allerdyce

A warm welcome to Claudette who joins the Sickle Cell Society as a new trustee.

Claudette is a pharmacist, with a career in NHS Organisations across London that spans over 25 years. She is currently the Head of Medicines Optimisation in South West London Integrated Care Board (ICB), which was previously South West London Clinical Commissioning Group (CCG) Claudette holds a Bachelor of Pharmacy degree from Kings College, University of London and a Masters' in Healthcare Commissioning, obtained at Birmingham Business School, University of Birmingham and has a cultivated substantial experience in strategic planning, and implementation of evidence-based practice within the UK health Service.

Claudette is passionate about addressing health inequalities and eliminating barriers that prevent people from navigating the health system and accessing equitable care. As a mother of a sickle cell warrior, she's experienced first-hand the challenges faced by the sickle cell community living in the UK. Outside of work Claudette continues to pursue an avid interest in health prevention and is a qualified health coach and former level 2 fitness instructor. In her spare time, she will use these skills to facilitate people to make lifestyle modifications to improve their health and reduce the risk of preventable illnesses such as type 2 diabetes, stroke, and cardiovascular disease.

We look forward to working with Claudette.

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HEALTHCARE AND RACE:

An interview with John James OBE by Artvocate's

Artvocate's written interview series allows our audience to learn more about the charities and organisations that we donate to.
O. D. Adedji is one of our Racial Justice artists. Her art explores heritage, legacy and contribution, revealing the beauty and dynamism of Nigerian culture to new audiences. Adedeji has chosen to direct her work's donations towards Sickle Cell Society, UK.

We were lucky enough to interview John James OBE: Chief Executive at Sickle Cell Society, UK. They tell Artvocate all about the organisation, along with their future plans and current thoughts on our artists and their work!

Sickle Cell Society works to support and represent those affected by Sickle Cell Disorder to improve their overall quality of life. Can you tell us more about the main focuses and what you do?

- Raising awareness by way of health information/education through a variety of formats, blogs, podcasts, e-materials. Resources on our website, webinars, conferences, workshops and events
- Delivery of direct services such as our Helpline and Information service (telephone, face to face and email) activities for young people living with SCD and their families such as our 3-4 day summer Family Retreat and our children and young people peer mentoring programme. We also encourage black and mixed race people to donate blood through our Give Blood Spread Love programme. We urgently need more black/mixed race donors not least because regular transfusions is one of the available treatments for people living with SCD.
- Supporting Industry, Life sciences sector eg Genomics England, Universities with SCD research to improve health and health outcomes.
- Lobby and campaign for policy changes to reduce health inequalities for the SCD community including through the All Party Parliamentary Group for sickle cell and thalassaemia.

What is your role within the organisation?

I am the Chief Executive of the charity. I provide the leadership for the organisation to achieve its strategic goals ably supported by a great small staff team and volunteers, with strategic support from our diverse and strong board of trustees. At all levels in the organisation we have people who live with SCD or cares for someone who has the condition.

O. D. Adedji, Vee (left) and A Sign of Hope (right), pictures at Artvocate's Not on Paper exhibition (London, 2022)

O. D. Adedji, Yinka (2018), oil on wooden panel, 80 x 80 cm.

In our Racial Justice narrative, we bring focus to the inequities that exist within the healthcare system for the black community. Is this issue relevant within your line of work, and have you sees any progress?

The issue of racial justice and health inequalities for people living with SCD is particularly relevant to our work as a charity to bring about sustainable change and improvement to the health and health outcomes of people living with SCD.

SCD is a haematological red cell blood disorder. In summary red cells become sickle shaped when de-oxygenated. The cells are also less supple than normal round blood cells. As a result of the sickling the red blood cells become trapped in blood vessels causing severe pain (sickle cell crises) and also long term damage to the organs. One patient described a crises to me as someone 'hammering a nail into her joints'.

Let's not forget the impact on mental health and well-being. SCD affects all aspects of one's life.

Whilst SCD is truly a global condition, it predominantly affects people whose heritage is from Africa, the Caribbean and Asia. SCD is the most common and fastest growing genetic blood condition in England with approximately 17-18,000 living with sickle anaemia, in contrast to the many more people who are healthy carriers (trait) of the condition.

SCD is an underserved and overlooked condition by policy makers. It has been this way for decades. People living with SCD experience significant NHS care failings which has resulted in unnecessary deaths of patients as well as negative attitudes linked to race. All of the evidence associated with the NHS care failings of people living with SCD are outlined in the All Party Parliamentary report; No One's Listening (available at no cost on the Society's website).

What has your organisation been working on recently, and do you have any future events that you're excited about?

There is quite a lot going on. Apart from following up on securing change through the recommendations from the No One's Listening report, we are currently working with NHS England and SCD patients and their families to improve access to automated red cell exchange across the country. Unfortunately, it is a bit of a post code lottery.
We are also rolling out our evidence based children and young people's peer mentoring programme in London and also other parts of the country.
We will be holding a conference with our public health partners and partner charities on 18 April about ante natal screening not only to highlight collaborative work we have undertaken but also to improve the screening pathway.

One of our artists, O. D. Adedeji, is directing their artwork's charitable donation to your organisation, Sickle Cell Society. Their work Yinka explores mental health within the black community. What are your thoughts on this piece, and do you feel it can help spread awareness for racial equity within healthcare and beyond?

I like O.D Adedeji's work entitled Yinka. My thoughts on this piece are: first, it resonates with mental health and well-being for people living with SCD because this (the psycho-social impacts of SCD) is a significant factor for children and adults living with this condition.
Secondly, SCD is an invisible condition – the image portrays some of that invisibility but at the same time it also portrays how sometimes people (in this case, health care professionals) only see one's blackness/colour, which can bring about racist and negative attitudes.
Thirdly, Yinka shows pain/anguish in the eyes of one of the individuals which clearly resonates with SCD and painful crises. However, in the eyes of the other person there are signs of hope. It motivates me and our work as a charity, to make that hope a reality. I certainly think it can help spread awareness for racial equity in healthcare and beyond. It will have meaning to many people who live with SCD and their families.

UPDATE

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

Iyamide Thomas, NHS Engagement Lead (Screening Programme)

We are now nearing the end of the current 'Engagement Project' commissioned by the NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme) in August 2018, to work in collaboration with the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) and help ensure the screening service is underpinned by service user needs and addressing any inequalities. Any subsequent contract will be with NHS England (since Public Health England was dissolved) and will be commissioned by public tender. Meanwhile, below is an update on the project's key achievements over the last ten months.

Service User Experiences of the Sickle Cell and Thalassaemia Screening Pathway

You might recall from previous updates that the project's main work-stream over the last year has been a consultation with mothers, fathers and individuals who have not yet had children (i.e. 'preconception'), to gain feedback on their experiences of sickle cell and thalassaemia screening. These groups provided very useful information, some of which will ultimately feed into the NHS SCT Screening Programme review of their '*Protocol for Reporting newborn screening results for sickle cell disease to parents'* targeted at health professionals, which was last updated a while ago and will this time include useful insight from parents who receive a thalassaemia diagnosis for their newborn child. This work-stream will show how people at-risk of carrying the sickle cell or thalassaemia gene are being consulted via the Societies and are subsequently influencing Screening Programme policy. This consultation with users of the Screening pathway culminated in a report *'It's in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia'* being launched at a national conference by the SCS, UKTS and NHS SCT Screening Programme on 18 April 2023 at Mary Ward House in central London.

The 'hybrid' conference (i.e. both in-person and online) attracted a total of 168 stakeholders (47 in-person and 121 online) including health professionals, researchers, medical students and service users. The conference was chaired by Dr Elizabeth Dormandy, former Chair of the Engagement Project Advisory Group and Scientific Advisor, Sickle Cell Society (Retired). After Amanda Hogan, NHS Sickle Cell & Thalassaemia Screening Programme Manager gave an overview of the service user consultation project and how it fits in with the Screening Programme's service delivery, presentations were given on: *'Antenatal Screening and Counselling', 'Newborn Screening', 'Service user experiences of the screening pathway', 'Service User Stories- a Collaborative Project', 'NHS SCT Screening Programme Protocol for Communicating Newborn Screening Results', 'e-Learning Resource'* and *'Preconception Screening Outreach'*. It was particularly pertinent that we had two sickle cell service users present who spoke of their experiences and also two medical students who spoke about outreach they'd like to see happen to raise awareness of preconception testing.

You can download the *'It's in Our Genes'* report here: https://www.sicklecellsociety.org/resource/its-in-our-genes/

Outreach

Outreach is a continuous work-stream of the project and the SCS and UKTS use their respective networks to raise awareness to the public and health professionals on screening issues, as well as general awareness of sickle cell and thalassaemia. During the pandemic, a lot of our outreach was successfully done online with talks, events and social media. Subsequently, we now do a combination of in-person and online outreach. On 1st October 2022 the start of Black History Month, I did a pre-recorded presentation on sickle cell for the Thackary Museum of Medicine in Leeds as part of their 'Insights Lecture' series and feedback is that it was well received by the packed hall. The presentation was also put on their website. As part of their Black History Month awareness, I was interviewed for a comprehensive

Seyi Afolabi and Iyamide Thomas run awareness stall for Rare Disease Day

Iyamide gives feedback from Mothers

Bimpe and Zenni talk about preconception outreach

Sarah Barnes, Lead Clinical Nurse Specialist for Haemoglobinopathies Antenatal and Newborn Screening, Leicester Royal Infirmary talks about some challenges in delivering newborn screening results

Cross section of conference participants

John James, CEO Sickle Cell Society summing up

podcast covering sickle cell, its history, screening, blood donation and more by the Department of Environment, Food and Rural Affairs (DEFRA) who shared this podcast with their 30,000 Defra group staff members and to an external audience through promotion via their social media channels. You can listen to this podcast here: https://www.youtube.com/watch?v=FWDFNm4wCe8

In commemoration of Rare Disease Day (which is on 28 February), University of London's Royal Holloway College held their annual event on 27 February 2023 at which my colleague Seyi Afolabi and I ran an awareness stall. It was a very productive day with lots of university students and school children coming to find out about sickle cell, screening, blood donation etc.

When a service user saw our social media posts on the event, she asked me if sickle cell was a 'rare disease' and after checking the definition, my response to her was *"even though millions have sickle cell around the world, a "rare" disease is defined as one which affects fewer than 1 in 2000 people in the general population. Most genetic conditions apparently fall in that category."*

PERICLES (Prenatal Therapy for Sickle Cell Disease)

I represent the Society on a King's College research project called 'PERICLES,' which is seeking to find out stakeholder views and attitudes towards Prenatal Therapy for sickle cell disease, a future treatment using stem cell transplant to effectively cure affected babies in the womb. Interviews with stakeholders have commenced and as of end of April, thirteen interviews had been conducted with ten women and three men, so yet again we need more men! So far, several interviewees are in favour of prenatal therapy, although some raised concern on how it might affect the baby once born. We still need people from the following categories:

- Religious people – most people interviewed so far are Christians and the project would like to interview people from other faiths and /or those in leadership roles such as priests, pastors or Imams.
- Doctors (e.g. haematologist, paediatrician, obstetrician)
- Men

Please email me if you are interested in participating or know someone who is: iyamide.thomas@sicklecellsociety.org

For more information on the project please visit the website: https://www.kcl.ac.uk/research/pericles

Once again, this update gives you an overview of progress with the Engagement Project (mainly from the Sickle Cell Society perspective). For more comprehensive information on the project please see the annual progress reports available on the Sickle Cell Society website: https://www.sicklecellsociety.org/screeningprogramme/

This Valentine's Did You Find Your Type?

By Iyamide Thomas, NHS Engagement Lead (Screening), Sickle Cell Society UK

We celebrated Valentine's Day back in February. Did you know it is reportedly the most celebrated day around the world besides New Year? Saint Valentine's Day is apparently named after a saint called Valentinus who it is said was imprisoned for performing weddings on soldiers forbidden to marry and for ministering to Christians who were persecuted under the Roman Empire. Legend has it that he healed the daughter of his jailer and before his execution he wrote "*from your Valentine*" as a farewell to her! By the 15th Century, 14 February had become associated with romance and the tradition of courtly love and had pretty much evolved to what happens now – an occasion when couples (current or would-be!) express their love by presenting each other with flowers, chocolates, romantic gestures and cards known as 'valentines'.

Why Care about Type?

From the type of people we might have been attracted to this past Valentine's Day to the way we look and behave, there's a lot we inherit from our parents through genes, including our **haemoglobin genotype.** This tells you the two genes (i.e. codes) – one inherited from each parent – that determine your type of blood haemoglobin. Haemoglobin is the substance in your blood that gives blood its red colour and carries oxygen around your body. The type of haemoglobin genes you inherit or pass on can play an important role in determining whether you or your children are affected by two serious inherited blood conditions – **sickle cell disease** and **thalassaemia**.

Sickle cell disease is a serious inherited blood condition that can cause severe pain, anaemia and organ damage. It mainly affects people who originate from Africa, the Caribbean, Asia, the Middle East and the Mediterranean. However, sickle cell is not a 'Black' disease and can affect 'White' people too, though less frequently. The reason sickle cell is more common amongst the ethnicities described above is because the sickle cell gene was a mutation to protect against malaria and being a 'carrier' of **one** copy of the gene (also known as being 'trait') offered some protection. People with the trait survived malaria and could have children with other survivors, thus making sickle cell prevalent in areas that had malaria. Thus, it is not a condition people should feel stigma about. Also, please remember trait or not, everyone should protect themselves when in malaria areas of the world!

Out of the 15 million people estimated to have sickle cell disease worldwide, around 10 million live in Africa of which approximately 4 million are in Nigeria. In the UK, an estimated 15,000 people have sickle cell disease and in 2019/20, 262 new babies were born with sickle cell and 8247 were 'carriers' or 'trait' (Data from NHS Sickle Cell and Thalassaemia Screening Programme Data Report 2019/20).

Thalassaemia is a condition most common among people originating from India, Pakistan, Bangladesh, Cyprus and China. People can inherit Beta Thalassaemia major which affects their ability to produce enough red blood cells. This causes severe anaemia and organ damage and they need to be on regular blood transfusions throughout life.

The usual and most common type of haemoglobin gene people inherit is Haemoglobin A. Unusual haemoglobin genes include Haemoglobin S (known as 'sickle haemoglobin'), Haemoglobin C and beta thalassaemia. People can only get sickle cell or thalassaemia if they inherit **two** unusual genes for haemoglobin, one from each parent. In the UK 1 in 4 West Africans are sickle cell 'trait'.

Post Valentine's be the perfect partner!

On 14 February 2023, many people will have established new relationships or progressed further with old ones. Particularly for young couples who have not yet had children, now might be the right time to raise awareness of these two inherited blood conditions so individuals can consider finding out their 'haemoglobin genotype', as each time two people with trait have a baby there is a 25% chance the baby could be born with sickle cell disease or thalassaemia. A simple blood test will determine if you carry a gene for sickle cell or thalassaemia and tell you your haemoglobin genotype. For someone with sickle cell anaemia this will be 'SS' and for someone with sickle cell trait this is 'AS'. However, if people inherit the other unusual haemoglobin genes they will have other types of sickle cell disease apart from sickle cell anaemia, such as 'SC Disease' (common amongst Ghanaians) and 'sickle-beta thalassaemia'. There is an NHS Sickle Cell and Thalassaema (antenatal and newborn) Screening Programme which offers all pregnant women a screening blood test which is then offered to the father-to-be if the woman is found to be a carrier. The Programme also screens newborn babies for sickle cell. In England only 60% of men are currently accepting their invitation for sickle cell screening and so more men need to step up! If the father-to-be also carries the sickle cell gene then the 'at-risk' couple is given all the information that enables them to make an informed choice about the pregnancy. **If you are already a couple and you know that you both carry one of the genes for sickle cell or thalassaemia then you should present to your GP early in your pregnancy or contact maternity services or your nearest NHS Sickle Cell and Thalassaemia specialist counselling services directly.** You should also tell healthcare professionals if you want counselling and prenatal diagnosis (tests to see if the unborn baby has the condition) and not assume that all healthcare professionals will know what you want!

Preconception Testing

Testing for your haemoglobin genotype before pregnancy is called 'preconception testing'. You can ask your GP for this blood test before you and your partner decide to start a family and especially if you know other family members who are carriers or who have sickle cell. You and your 'Valentine' can then discuss any risks and the choices that are right for you! Recent discussions the Sickle Cell Society has had with students and young adults who have not yet had children indicate that there is now more awareness of sickle cell and that many are keen to find out their genotype before starting relationships. They are also keen to know options available to 'at-risk' couples. The Sickle Cell Society and UK Thalassaemia Society do a lot of outreach to educate the general public about sickle cell and thalassaemia as more awareness will also help to remove the stigma associated with these two conditions. The Societies are also planning to do even more preconception outreach so those planning children will be well informed.

Now the valentine cards, chocolates and flowers are over why not learn more about sickle cell disease and thalassaemia so you can make informed choices (about testing) if and when the need arises? By so doing, you just might be considered that perfect partner after all!

Below are websites with lots of information to help you:

Sickle Cell Society
www.sicklecellsociety.org
E: info@sicklecellsociety.org
UK Thalassaemia Society
www.ukts.org
E: office@ukts.org

TRIBUTE TO NORDIA

It was with great sadness last October that the Sickle Cell Society learnt of the passing of Nordia Ann-Marie Willis.

Nordia advocated for Sickle Cell since childhood, taking every opportunity to speak out and spread awareness of this debilitating disease. At 18, Nordia Co-founded "Broken Silence" in memory of Leona Dehaney, raising awareness through school campaigns, annual charity events and lobbying the government to make constitutional changes for Sickle Cell through the APPG for Sickle Cell and Thalassemia.

Nordia worked alongside NHS management and staff, researchers and academics. Shaping and changing how professionals think and work. Improving health for others in the future.

Eddie from NIHR UCL Hospitals Biomedical Research Centre wrote: 'Although I only met with her on a few occasions like so many others I'm sure I too was in awe of her dedication to furthering the cause to promote and educate about the plight of those who suffer with 'Sickle Cell Disease' so that improvements can be made.

There are no words that can fully capture how the loss of Nordia have left me feeling, but she leaves me with a greater personal awareness of Sickle Cell Disease (*and the associated charities that provide a home of support for all those affected by it*) and with an increased determination to help further the cause that she was so passionate about.

All that Nordia shared is an inspiration to continue with the important work that she was and remains part of.'

Nordia's kind heart, passion and love for life, warmth and uplifting spirit, sense of humour and exquisite beauty will be deeply missed.

FUNDRAISING SPOTLIGHT

On 14th April, the Lord Mayor of Leicester kindly invited the SCS to take part on a sponsored walk organised by Leicester United in aid of the SCS. Leicester United is an umbrella organisation that brings together Leicester's Football Club, Riders Basketball Club, Country Cricket Club and Leicester Tigers Rugby Team.As we are the Mayor's chosen Charity for his year in office, we are deeply honoured by his support. The walk was very well organised by Leicester United and we had the support of Steve Walsh, former LFC professional footballer. It was a great day that brought together SC families and supporters of our walk. In true British style, we had rain but that didn't damped the spirits, if anything it made it better as no one was fazed by it. Thank you to the Lord Mayor, Lady Mayoress, Leicester United, Leicester Council and all the participants.

Lord Mayor of Leicester

Participants

Huge congratulations to Steven Birch who run the London Marathon 2023 on 23rd April to raise funds for SCS. Steve trained hard to prepare for the race and raised over £1,000 too! Well done Steve!

Leicester United Sponsored Walk

Lord Mayor, Lady Mayoress, Steve Walsh and Mayor's Leicester Council Team

Steven Birch at the finsh of the London Marathon

LET'S CELEBRATE

Thank you so much to Patricia, Sona and Leon and everyone at Let's Celebrate for organising a wonderful ball in Northampton which was attended by our CEO, John James

For the second consecutive year, employees of the Metro Bank have enthusiastically run a raffle that raised £2976! Thank you ever so much!

WORLD SICKLE CELL DAY: CELEBRATING PROGRESS

On the 19th June we joined with others around the globe to celebrate World Sickle Cell Day, a United Nation's recognised day to raise awareness of sickle cell across the world.

This year our theme was "Celebrating Progress". As a society, we felt that we have much to celebrate including the progress made in recent years in terms of medical advances for people living with Sickle Cell, Improved Standards of Care (through our No one's Listening campaign)m raised awareness to talk about topics like Priapism and more opportunities for service-user voice as demonstrated through our recent survey on red-cell automation run in conjunction with NHS England.

Our mission still remains to represent people, patients and families affected by sickle cell disorder to improve their overall quality of life and whilst much progress has been made, we recognise that there is always more that can be done and so we will be striving to make more progress for people living with Sickle Cell.

EMMANUEL AMUTA POETRY AWARDS

The Emmanuel Amuta Poetry Award is a creative competition for young people (between ages 10-15 years) who have sickle cell. The award has been created in memory of Emmanuel Amuta who suffered from sickle cell and sadly passed away on 19 September 2017, age 14 years.

Emmanuel was a confident, caring and gifted young man most cherished by the Sickle Cell Society. He was good at poetry and rap and really endeared himself to participants at the Society's AGM in July 2016 when he narrated his poem 'A Beautiful Cell'. This award will be his fitting legacy.

This year, the winners were announced during our storytelling workshop on Wednesday 26th October.

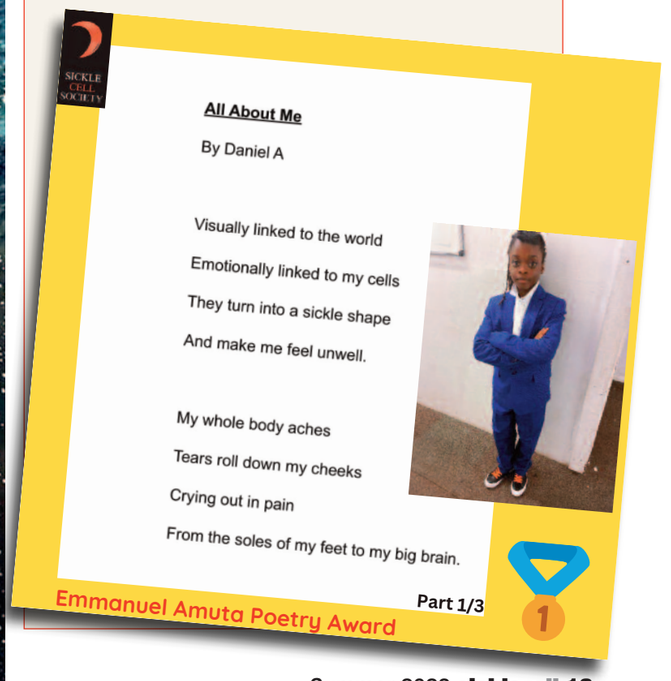
Here were the winners:

1st **Daniel** (winning £50)
2nd **Tiffany** (winning £30)
3rd **Victoria** (winning £20)

The runners up were from two young people with Sickle Cell and a sibling of a child who has Sickle Cell
Ahuoyiza, Ralph and Jessica

A massive well done and congratulations to all the participants!"

Taja Morgan



8 Tips on Navigating University with Sickle Cell Disease for Students

By Chineme Iloh

As a young woman with sickle cell disease, starting university was an exciting but nerve-wracking experience for me. I was navigating this unfamiliar environment away from home, exposed to a myriad of new people from various backgrounds, and caught up in the excitement of trying new things, getting involved in societies and making friends.

However, university is also a stepping stone towards independence. Before university, I had the comfort of relying on my family for support in the event of a crisis. However, transitioning to university reminded me that I would have to be highly intentional when taking care of myself, in order to stay healthy and avoid the event of a sickle cell crisis (which becomes even more daunting when you're in an unfamiliar city by yourself, away from home). Therefore, I wanted to do all I could to look after myself, whilst enjoying the full university experience and studying for a degree.

I recommend the following tips to students with sickle cell disease (SCD) on staying safe and healthy at university:

Get in touch with your university's well-being support team.

Every university has a dedicated disability and/or well-being support team for students. By contacting the team, you'll be allocated an advisor who will support you throughout your time at university. Their support can be helpful if you need to catch up on missed lectures due to hospital appointments, or if you need extended deadlines on assignments. Your advisor can also coordinate with your academic department and advocate for you in the case of a crisis.

Choose your student accommodation wisely.

Before starting university, you tend to have a selection of student accommodations to choose from. Before selecting one, think about whether it meets your criteria. Is it close to the central campus? Does it have an ensuite bathroom? Does it have an elevator (for buildings with multiple floors)? For example, it was essential for me to live in accommodation close to my lecture theatre and seminar classes, so that I would not have to walk far distances every day, especially during the winter.

In some cases, reasonable adjustments can be made so that your accommodation fits your criteria. For example, you can request to have the heat turned on in your room earlier in the year than usual. Consider the best accommodation for you and any adjustments that can be made, as you'll be living there for the entire academic year.

Know your "triggers" and try to avoid them.

"Triggers" increase the likelihood of a sickle cell crisis. Typical triggers include dehydration, exhaustion, extreme temperatures and stress. University is a difficult environment to avoid these triggers, but as a student with SCD, it is important to understand your triggers and find the best ways to prevent them. Developing methods to avoid your triggers, such as time-blocking your assignments, unwinding after a full day on campus, and ensuring you get enough rest after a night out, is key to your well-being.

Manage your stress levels.

Every student feels the pressure of large assignments, approaching deadlines and final exams. As a student with SCD, finding a balance between the time you spend studying and resting is essential. Stress is a key trigger of sickle cell crises, and a crisis during a critical period, such as exam season, can be extremely inconvenient and demotivating. Therefore, start working on projects early and break down your assignments into small, manageable chunks, to ease the workload each day.

Plan ahead, especially for large projects and exams.

Sometimes hospital appointments are scheduled during my timetable at the same time as an exam or approaching deadline. Therefore, it is important to plan ahead and have contingencies in place. Reach out to your department and coordinate your appointments with your disability services team, so that they can arrange for mitigating circumstances or an alternative time to sit the exam if something arises. While health should always be your biggest priority, careful planning in advance ensures that your education isn't compromised either.

Practise healthy habits and form a routine.

University is a great time to form new habits and routines. One of my goals as a university student was to be more active and eat healthier meal options. Between lectures and during study sessions with my friends, I eat home-cooked meals or salads to keep me going. Other habits include drinking plenty of fluids and getting enough sleep each night. These habits can help to reduce the frequency of a crisis, and you'll feel more energetic throughout the day.

Similarly, forming a daily routine can help you develop a structure for university life. For example, waking up and going to bed at the same time each day allows you to be more productive and approach each day with a similar rhythm.

Build a support network.

When I started university, I was initially very apprehensive about telling people about my SCD. I was worried that I wouldn't be able to make friends or that people would look at me differently. However, when I made friends I could trust, I realised that it was beneficial for them to be aware of my condition. During a crisis, my coursemates would fill in for me by sharing their notes for the lectures I missed, and my friends would check up on me with snacks and movies to ensure I was okay. Let your friends, advisor, and professor know about your SCD.

Enjoy your university experience to the fullest.

University is much more than just attending lectures and late-night study sessions in the library. University is also about joining societies, getting involved in activities, meeting new people and trying new things. You should aim to make the most of your experience, whilst taking precautions to ensure your health remains a top priority, but most importantly, just have fun!

In conclusion, although managing sickle cell disease as a university student can be challenging, it is possible to stay healthy, socialise, and excel in academics, with intentional self-care, communication with professors and peers, and the utilisation of campus resources. By prioritising your health and well-being and seeking support when needed, you can still enjoy the full university experience.

Sickle Cell & Thalassemia APPG meeting of 2023

"On Monday 20th March we successfully held the first Sickle Cell & Thalassemia APPG meeting of 2023. The committee and attendees had rich discussions on the progress of the 'No One's Listening' report. The agenda also included;

Cost of living crisis, impact on Sickle Cell patients

Janet Daby MP Chair of the Sickle Cell & Thalassemia APPG

The National Haemoglobinopathy Panel Five Trust Focus Areas

Dr Baba Inusa Chair of the National Haemoglobinopathy Panel
John James Chief Executive of the Sickle Cell Society

New SCD modifying treatments

John James Chief Executive of the Sickle Cell Society

Free Prescription Alliance updates

Laura Cockram Head of Policy – Parkinson's UK and Prescription Charges Coalition

The meeting discussions highlighted some good work happening in areas. However, there was emphasis on the scale of work that remains to be achieved to improve the quality of care and quality of life for those who live with sickle cell".

Take part in a Research Study

Vision Serenity are looking for Volunteers to join their Sickle Cell Study Research Programme of VIT-2763 – a new potential treatment under development for the symptoms of Sickle Cell Disease

The purpose of this study is to explore the safety, tolerability and effectiveness of a study drug called VIT-2763 for sickle cell disease (SCD). Specifically, we want to investigate its effects on the breakdown of red blood cells and inflammation associated with sickle cell disease.

To take part, you must

- Be 18 to 60 years of age
- Have SCD, including HbS/S or HbS/ T0 genotype (but NOT HbS/ T+ genotype or HbSC disease). The study doctor can tell you what kind of SCD you have if you are not sure.
- Have had 1-10 vaso-occlusive crises within 12 months prior to study screening. These are also called 'sickle cell pain crises' or 'VOC episodes'.
- Not have chronic liver disease or a history of liver Other criteria will also be reviewed to see if you can take part.

If you are interested in finding out more, or participating in the study then please visit our website to find your nearest Trial Location.

What is a clinical study?

A clinical study (also known as a clinical trial) is designed to learn more about a drug's ability to treat a specific disease or condition. Regulatory agencies and health authorities use the results of clinical studies to decide if a drug should be made available to patients. A drug used in a clinical study has not yet been approved for the treatment of a disease, but it is being tested in clinical trials to see if it should be approved as a future treatment option.

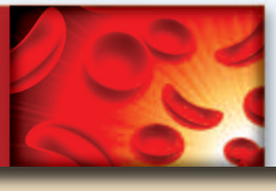
Clinical studies are conducted by experienced and trained medical professionals who monitor the health of participants throughout the study. Also, every clinical study is reviewed by an independent review board (IRB) or ethics committee (EC), which helps ensure that the study is conducted safely and that the rights of study participants are protected.

What is the purpose of this study?

The purpose of this study is to explore the safety, tolerability and effectiveness of a study drug called VIT-2763 for sickle cell disease (SCD). Specifically, we want to investigate its effects on the breakdown of red blood cells and inflammation associated with sickle cell disease.

What is the study drug?

VIT-2763 targets and blocks a protein in the body called ferroportin. Ferroportin allows the body to transport iron to the blood stream. Iron is important in the production of haemoglobin, the protein that transports oxygen in red blood cells. It is expected that, by blocking ferroportin, VIT-2763 may lower the iron level in the blood. This might reduce the concentration of abnormal haemoglobin (sickle cells) in the red blood cells, and it may reduce the destruction of red blood cells caused by SCD.



VIT-2763 is being developed by Vifor International Inc., the sponsor of this study. It has been tested before in healthy volunteers at multiple dose levels and was well-tolerated by study participants. VIT-2763 is also being tested in people with another blood disorder called thalassemia.

What is a placebo?

Placebos are used in clinical studies so that researchers can understand what effect a new investigational product might have on a condition. A placebo looks like the study drug, but does not contain any active substance. In this study if you qualify, you have a 1 in 4 chance of receiving placebo.

Who can be in this study?

To take part, you must:

- Be 18 to 60 years of age.
- Have SCD, including HbS/S or HbS/βT0 genotype (but **NOT** HbS/βT+ genotype or HbSC disease). The study doctor can tell you what kind of SCD you have if you are not sure.
- Have had 1-10 vaso-occlusive crises within 12 months prior to study screening. These are also called 'sickle cell pain crises' or 'VOC episodes'.
- Not have chronic liver disease or a history of liver cirrhosis.

Other criteria will also be reviewed to see if you can take part.

What does it mean to be involved in this study?

Approximately 24 patients will take part in this study, at institutions located in a number of countries including the United States of America.

The study lasts about 16 weeks and is divided into 3 main periods:

- **Screening/Baseline (up to 4 weeks):** Your medical history will be reviewed, and other tests will be done to see if you can take part in the study.
- **Study Treatment Phase (8 weeks):** If you qualify, you will be randomly assigned (like rolling dice) into 1 of 4 different study treatment groups with various doses of VIT-2763 or placebo. You will have a 3 in 4 chance of receiving VIT-2763 and a 1 in 4 chance of receiving placebo. You will take the oral study treatment twice or three times daily and attend 5 visits for study-related testing.
- **Follow up (4 weeks):** You will return to the study clinic 28 days after the end of study treatment for one final health check.

Why participate in the study?

Treatment options for people with sickle cell disease are limited. This study will contribute to the development of a potential new treatment. Participants will also receive medical monitoring throughout the study that may provide additional health insights.

Taking part in a clinical study is completely voluntary. If you enrol, you can choose to leave the study at any time and for any reason and it will not affect your usual care.

What is the Informed Consent Form?

Before joining the study, the research staff will review a document with you called the Informed Consent Form (ICF). This document provides much more detail about the study, the tests being done, possible risks and side effects, and your rights as a participant. You should read the ICF carefully, ask questions, and talk to the study doctor about any concerns you might have.

Will the study cost anything?

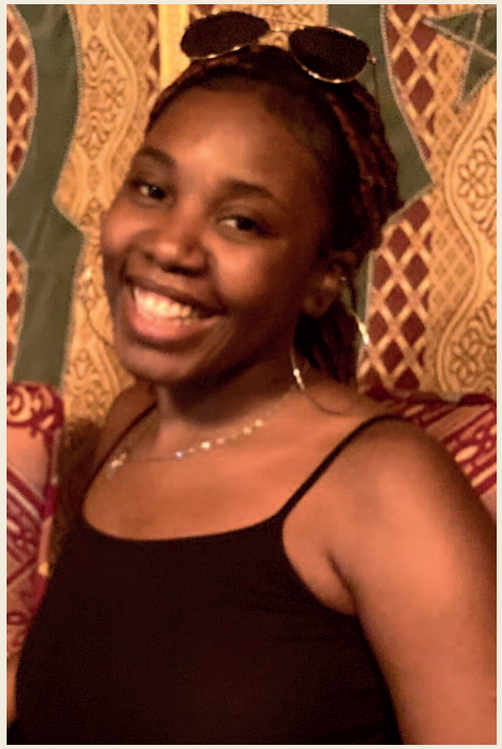
The study treatment, visits, tests and procedures that are needed in this study are provided at no cost to participants. The ICF or the study staff can tell you about any reimbursement that may be available.

Sickle Cell and Blood Transfusion – the Future

Congratulations to Martin Besser Äi Consultant Haematologist at Addenbrookes Hospital, Cambridge who organised an excellent event recently called "Sickle cell and blood transfusion - the future". This event took place in collaboration with the Sickle Cell Society and a range of other partners like NHS, BT and others in industry. The event was well attended by patients from Cambridgshire and Suffolk. Thanks to all who attended.

VICTORIA SAJOWA

shares her thoughts on Sickle Cell and Doctorhood



Having a crisis during a lecture is not ideal, having to call the ambulance at night around housemates you've JUST met is not ideal, having to visit a health centre at 2am alone because you didn't want to wake anyone up is not ideal, having to complete your final medical schools exams in a wheelchair is.. not...ideal. Medical school is hard, going through medical school with sickle cell disease is ever harder.

From the age of 6, I knew exactly what I wanted to be. The journey from there to now has been a rollercoaster, full of highs, lows and everything in between. Despite all the crises, medications, and blood transfusions since birth, in 2022 I finally became a doctor.

Prior to medical school, I had never really considered myself an advocate for my condition. I was never shy about it and told people that needed to know; however, I rarely spoke about my experience living with it. This changed in medical school. I remember being in a lecture on blood conditions, sickle cell came up and I thought YES here we go. Until it ended up being summarised to two lines on the bottom of a slide, which essentially just said that sickle cell is a disease in which patients complain of pain. I was disappointed to say the least, I was not expecting an entire lecture, but I thought more than that.

Following this, I was motivated to speak about sickle cell more often. I began with my friends on the course, most of whom knew very little and for many I was the first person they knew with the condition. But having experienced many interactions with healthcare professionals, hearing comments such as "what is sickle cell?" and "is it really that painful?". I felt it was my duty to make sure my colleagues/friends who were going to be doctors knew more. So that at least one person in crisis was made not to feel worse than they already do, by having to also explain their entire condition. I made sure to iterate the importance of analgesia and fluids, and not confusing someone who was not bawling as someone who was "not in that much pain".

During my degree I became involved with different projects to keep increasing awareness. One team was a collective who edited medical cases for year groups to work on during seminars. Through this I was able to include resources and content in cases across all the years about sickle cell disease to raise awareness. Additionally, I was asked to be "patient of the week" for one of the cohorts, in which I spoke about my condition, blood transfusions, symptoms and how it is managed. I do not think there had ever been a patient of the week who spoke about sickle cell disease prior to that so I was thrilled to be involved in talking about it with a large group of students and answering all the questions that they had to the best of my ability.

In my final year alongside one of my friends, we aimed to help organise a blood drive at our university. This was to help increase blood donations in the area especially from the black community, and simultaneously raise awareness for sickle cell disease. Unfortunately, we were not able to do this, due to logistics. But alongside NHS blood and transplant, we were able to set up a stand in association with sickle cell society UK and raise awareness to many medical students across different cohorts that way.

I would like to say all medical school was, was studying, socialising, and advocating for sickle cell. But that was not the case I had umpteen crisis episodes at the most inconvenient of times, but my worst experience was during my final year exams. Nearing finals I was overwhelmed with emotion and stress. I could not believe that despite everything I had experienced I had final reached my final year. I got through the first set of exams just fine, the second set fine. Before the last set I started to feel a pain in my foot which I initially ignored, a few days later my foot was swollen and in agony and I started limping. I delayed seeking help because of finals but when I could no longer deal with the pain I went to the hospital and the pain was dismissed as a crisis, I was sent home with crutches and painkillers. The pain did not subside, and when it reached its peak, it was the day before my final exam of finals, I was determined to complete my exams whatever it took. This led me to having to reach out to the medical school the day before asking for some adjustments, this presented in the form of me examining patients, asking questions, and being quizzed, whilst being pushed in a wheelchair. I completed my exams successfully and that night was admitted into the same hospital I had just finished medical school in for 2 weeks. I could not make this up.

By some miracle, I passed.

I have so many more stories of getting through education, work and life itself in agonising pain. Now I am aware that there were a few times I should have sought help earlier and did not because I was trying to prove something to myself and others. I wanted it to be a, "I did it despite of", and not an "I couldn't do it because" moment. This is not something I advocate for at all and is something I am trying to unlearn as I realise, I have nothing to prove to anyone as long as I am looking after myself.

Starting work in 2022, I was excited. I, of course had all the important meetings required to make my seniors and team aware of my condition, how it would affect my role and adjustments that would need to be made for me to do my job effectively. Initially things were looking okay until the brutal winter, where I was hit by crisis after crisis. Then when it was not crisis, it was general pain. This is when I really got to know about the complications associated with sickle cell. First being when I discovered I had gallstones. Weeks later I was hit with another incredible bout of pain and shortness of breath and came to discover I had pneumonia (chest infection) and a pulmonary embolism (a clot in the lungs). During this episode I learnt how prone I was to developing these complications, something I had never truly understood. This took me out of work for almost a month, I could not believe I was finally a doctor and my sickle cell and side effects of it were worse than ever.

This was a horrible experience. It sucks to realise that it likely will not be my last. Despite this, my compassion and empathy for my patients has skyrocketed, it was always there because I've always been a patient and can relate in that way. But when you have experienced the exact same things as someone you are looking after the level of empathy is different. Through this I have no doubt in my mind that I am in the exact career I was meant to be in. I feel like I will be able to relate to my patients in a way not all the people looking after them will and that's what keeps me going.

By no means do I want this to seem all doom and gloom. Yes, I live with sickle cell disease and my life is not made easier by it to say the least, but I am wanting more than anything to destigmatise the condition by speaking more about it. I have been wary of sharing my experiences wholly in the past, but now I am grateful to be able to share it through this amazing platform doing great things for people just like me.

When I experience moments such as when my cousin, also a doctor, said to me "I met a patient with sickle cell and I remember what you said about the importance of fluids and analgesia first and I remember to implement that ASAP". It brings me hope that what I am doing in sharing my experiences both as a patient and as a doctor is not in vain.

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

PEER MENTORING

In April last year, we began the process of re-launching our peer mentoring programme in East London so that we can continue to help and support children and young people between the ages of 10-24 who are living with Sickle Cell.

In this time, we have been able to recruit, onboard and train mentors living with Sickle Cell to work with us on this programme. It was and still is important for us to secure recurrent funding for our programme and over the past year, we have been working hard to obtain funding to secure the future of our Sickle Cell Peer Mentoring Programme.

After many months and years of meeting and speaking with commissioners, North East London Integrated Care Board have agreed to fund the programme for a further 12-months (April 2023-April 2024). The next year will be dedicated to onboarding children and young people living in East London to our caseloads and getting them engaged in mentoring. We strongly believe that every child and young person living with Sickle Cell can reach their full economic and social potential with the right support and guidance from mentors on our programme.

Over the next 12-months, we will be working hard to achieve our key performance indicators and show our funders that once again, our programme is proven and successful. By the beginning of April 2024, we are aiming to get the Sickle Cell Society permanent recurrent funding for the programme and hopefully be able to take this innovative programme London wide.

How can you help?

We mostly receive referrals to our service from medical staff, nurses including specialist Sickle Cell nurses and allied health professionals. However, we also take self-referrals parents, carers and wider community workers.

We want to strongly encourage those living with sickle cell and carers of young people living with the condition to keep submitting self-referrals to our service.

If you have not yet submitted a referral to the service, please get in contact with the Sickle Cell mentor team via our email mentors@sicklecellsociety.org

SICKLE CELL IN THE SOAPS!

We were glad to see BBC One's Eastenders raising awareness for Sickle Cell.

During a hospital scene aired, the "Can you tell it's Sickle Cell" poster featured predominantly in a scene with Kim and Howie at the hospital.

It's great to see Sickle Cell being featured in the soaps!

SCS response to European Medicines Agency (EMA) and Committee for Medicinal Products for Human Use (CHMP) updates on Crizanlizumab

This statement is an update to our previous statement on Crizanlizumab made on the 31/1/23.

As many of you will know, Crizanlizumab (Adakveo) was recommended as a new disease modifying treatment for sickle cell anaemia by National Institute of Clinical Excellence (NICE) and NHS England on a Managed Access Agreement. This means that the treatment was recommended to eligible patients under an agreement to collect more data about it.

On the 26th May 2023, the European Medicines Agency's (EMA) Committee for Medicinal Products for Human Use (CHMP) made a recommendation to revoke the conditional marketing authorization for crizanlizumab, a once-a-month, humanized anti-P-selectin monoclonal antibody infusion indicated for the prevention of recurrent vaso occlusive crises (pain crises) in sickle cell disease patients aged 16 years and older.

Findings from a recent study did not confirm that there was a clinical benefit of the drug in successfully reducing the number of painful crises requiring a healthcare visit or treatment at home in patients with sickle cell disease and so the benefits do not outweigh the risks.

John James, CEO of Sickle Cell Society said

"Whilst the recommendation of the European Medicines Agency has been made, the decision of the Medicines Healthcare products Regulatory Agency (MHRA) for England is still awaited.

We would like to reassure UK patients who are currently taking Crizanlizumab (Adakveo) as part of the Managed Access scheme, that it is safe. However, if you have any questions, we recommend that you speak to your Consultant Haematologist who will determine the best options for each patient depending on their individual circumstances."

The CHMP's recommendation will be provided to the European Commission (EC) and a final decision will be made by the EC in the next two months.

As soon as we know the decision of the MHRA for England, we will update you again.

Helpline

The SCS Helpline Service provides confidential information, guidance, and emotional support to individuals and families affected by sickle cell living within the UK.

We understand that sickle cell disorders uniquely affect people, and can manifest into a range of further conditions. We also understand that a sickle cell disorder affects the wider social support network. That's why we support any individual affected by sickle cell, including family members, friends, employers, teachers and healthcare professionals.

The topics we cover include:

- Managing a sickle cell disorder
- Social and welfare issues
- Health and education provision
- Housing and benefits entitlement
- Employment support
- Emotional support
- Advocacy
- Accessing services
- Signposting to external agencies and
- Support groups

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

Monday, Tuesday and Wednesday (10am-5pm) – 0780 973 6089

Thursday and Friday (10am-5pm) – 0208 963 7794

More details and any changes can be found on our website: **www.sicklecellsociety.org/helpline/**

If you cannot get through to a member of staff, please don't leave a message but instead, call back later on.

You can also use our confidential email service: **helpline@sicklecellsociety.org**

Leaving a Gift

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

15,000 people in the UK live with sickle cell; a genetic blood disorder causing anaemia and episodes of severe pain. Over time people with sickle cell can experience damage to organs such as the liver, kidney, lungs, heart and spleen.

For the last 40 years, the Sickle Cell Society has been working alongside patients, families, and healthcare professionals to raise awareness, provide support and empower people living with sickle cell to achieve their full potential. The Society works both at ground level within the community and on a national level through campaigning for policy changes and supporting research.

By leaving a gift to the Sickle Cell Society you are joining that legacy and helping to improve the lives of future generations.

When you leave a gift in your will, we make a promise to continue supporting the sickle cell community. Your support enables us to reach more people, run more activities, and improve more lives.

After taking care of your family, why not leave a gift to support the Sickle Cell Society and help transform lives?

Find out more about leaving a gift in your will at:
www.sicklecellsociety.org/leaving-a-gift/
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 which takes place in July each year**

Our new Priapism Campaign

Did you know that most males with sickle cell anaemia (HbSS) will likely experience a priapism in their lifetime?

Priapism is a medical emergency that occurs when blood flow to the penis is not properly regulated, causing an unwanted erection that lasts for hours.

In June, we launched our new animation and information page on Priapism, raising awareness of painful penile erections in teenage boys with sickle cell disease and the need for prompt action.

The animation tells the story of Leon, a 13-year-old with sickle cell disease who recovers from a sudden and painful penile erection after his mother acts promptly, taking him to the Emergency Department (A&E).

This project is the culmination of a multitude of hard work by SCS and other stakeholders including Guys and St Thomas' Hospital and Boston Scientific to create a valuable resource for young men who may be experiencing Priapism.

Dr Rachel Kesse-Adu, consultant haematologist at Guy's and St Thomas', said: "Priapism is a common issue for young men with sickle cell and can affect up to 50%.

"It's important to raise awareness of the serious effects if priapism is left untreated. Dedicated resources are needed to help break any taboo and encourage families to talk about it."

Prompt care can help to prevent long-term complications and improve overall quality of life for those experiencing priapism. However, this requires knowledge of symptoms from both young sufferers and their caregivers, and a readiness to disclose the situation – which can be particularly embarrassing for children.

Mr Majed Shabbir, consultant urological surgeon at Guy's and St Thomas', said: "Attending the Emergency Department with an unwanted erection is the last thing any young man wants to do. But it is crucial if a prolonged erection lasts more than two hours, as delaying treatment can result in long-term damage to erections.

John James, CEO of the Sickle Cell Society, said: "This animation is a valuable resource for young people, parents and healthcare professionals to help understanding priapism, learn what to do about it, what to expect if there is a need to go to hospital, and to them equip with the language to talk about this issue.

To see the animation and to find out more about priapism visit www.sicklecellsociety.org/priapism

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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

We received a wonderful email from Winston, son of Gladys Weir, who very much enjoys reading the Sickle Cell Newsletter. Gladys is very happy to see so many positive things happening in the Sickle Cell community compared to when she was younger. We hope that you enjoy this issue Gladys!

www.sicklecellsociety.org/donate