SICKLE
CELL
SOCIETY

IMPACT REPORT

2025-2026

www.sicklecellsociety.org

ABOUT US

We are the UK's national patient charity dedicated to supporting people living with sickle cell disorder. Our mission is simple : to ensure everyone affected by the condition has access to high-quality care and the opportunity to live life to the fullest.

We stand alongside individuals, families, and communities, offering practical support, information, and advocacy. We work with healthcare professionals, researchers, pharmaceutical partners, policymakers, and community groups to raise awareness, influence policy, and campaign for better treatments and care. Everything we do amplifies the voices of those living with sickle cell and drives big changes that improve lives.

What we do

Advice Line | Give Blood Spread Love, England – blood donation programme | Children and Young Person's Peer Mentoring Programme Screening Programme | Sickle Cell Family Retreat | Volunteering Programme | Fundraising events | Campaigning and advocacy

ABOUT SICKLE CELL DISORDER

Sickle cell disorder affects more than 18,000 people in the UK and is the fastest-growing genetic condition in the country. It changes the shape of red blood cells from smooth, round discs to rigid, crescent-shaped "sickles". These misshapen cells are less flexible, break down more quickly, and can block small blood vessels, reducing oxygen flow around the body.

This can cause chronic anaemia, episodes of severe pain known as a "crisis", and, over time, serious complications such as organ damage, stroke, acute chest syndrome, infections, delayed growth in children, and priapism. Children between the ages of two and sixteen are at particularly high risk of stroke. Mental health can also be significantly affected.

Sickle cell disorder is inherited, lifelong, and, at present, has only limited treatment options. For those living with it, every day can present challenges – but with the right care, understanding, and support, people can lead rich, fulfilling lives.

COMMUNITY AT THE CENTRE

Our strength lies in the people around us — patients and carers, supporters and donors, medical staff and professionals working in the sickle cell space. Every project, campaign, and conversation begins with their voices. They shape what we do and how we do it, and we couldn't achieve any of it without the dedication of our community.

This year, our supporters have been extraordinary — taking on endurance challenges, creating birthday fundraisers, and finding countless ways to raise vital funds. From climbing Africa's highest mountain to pounding the streets in races and marathons, from radio appeals to collection tins, they've made it possible for us to support thousands of people living with sickle cell. We are deeply thankful to each and every one.

We also welcomed 9 new volunteers, bringing our total to 53 active volunteers who help run fundraising events, represent us at outreach days, and support awareness campaigns. Each one plays a crucial role in building connections and delivering impact on the ground.

This year we expanded our peer support programme, hosted our second family retreat, facilitated community workshops, and co-designed services with patients and carers. We listened — and with the community beside us, we delivered programmes that change lives. This is what patient-led, community-powered progress looks like.

COMMUNITY IMPACTS

Membership growth

Our membership increased by over 600, to 2990 members.

National reach

We are the umbrella organisation for 40+ support groups, voluntary organisations, and statutory centres across the UK.

Expanding online community

Our combined social media audience now stands at 33,000, spanning patients, families, health professionals, policymakers, and supporters. Meaningful collaborations this year helped us reach new audiences and amplify community voices far beyond our own channels.

Family retreat

27 families (100 individuals) from across the UK, from Croydon to Darlington, joined us from 30 August–1 September 2024 at Whitemoor Lakes for a weekend of education, adventure activities, networking, and fun.

Special moments

The family retreat was supported by Miffy, who made a popular character visit and provided children's gifts, and Pass The Bricks, who supplied LEGO.

Positive outcomes

100% of families made new friends and had fun; 100% of children learned something new about sickle cell; 87% of families had a new experience; 81% of children learned something new about themselves.

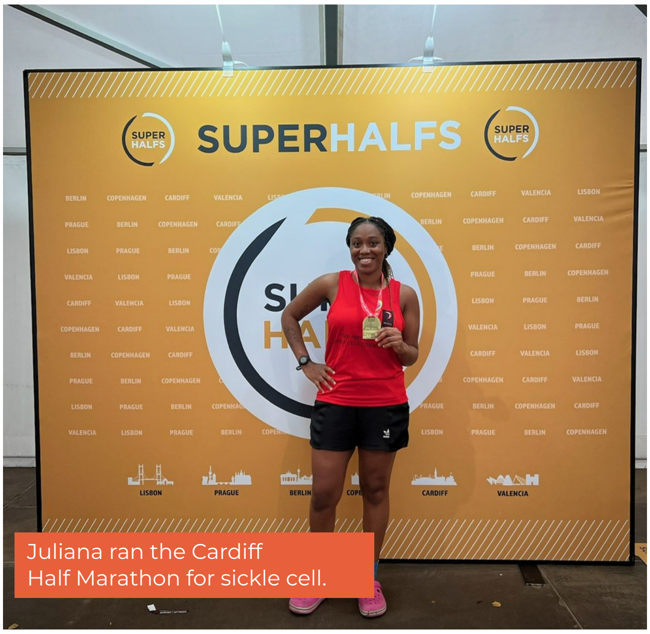
We delivered the Retreat thanks to the generous support of the Charles French Charity Trust, Pfizer, Hope for Sickle Cell, and The Dullatur Foundation.

> My son was so happy to meet other children his age with the same condition as him, he has felt isolated in the past with his condition, the activities were great, he came back with more knowledge of his condition and how he got. honestly a great weekend
>
> - Parent, family retreat

Family Retreat

David took on the challenge of climbing Kilimanjaro to raise funds for sickle cell.

Family Retreat



Juliana ran the Cardiff Half Marathon for sickle cell.

Family Retreat

INFLUENCE ON A GLOBAL SCALE

We may be a UK-based charity — but our reach is international. From thousands of global website visits to speaking engagements across the World, we are raising awareness, shaping conversations, and influencing policy far beyond our borders. Our campaigns resonate across communities and countries. When people around the world look for leadership and education on sickle cell, they come to us.

- **Website visitors:** 99,500, from over 100 countries around the world
- **Podcast downloads:** over 600, from across Europe, north and south America, Africa, Asia and Oceana
- UK representative member of the international Sickle Cell Disease Coalition based in the USA.
- Presented to the international sickle cell community at the ASCAT conference in 2024 (Annual Sickle Cell & Thalassaemia Conference, hosted by the Academy for Sickle Cell and Thalassaemia (ASCAT)
- Delivered talks and presentations at events internationally.

Our CEO, John James OBE, raising awareness of sickle cell through talks delivered both in the UK and worldwide.

BREAKING BARRIERS IN HEALTHCARE

Too often, people living with sickle cell face obstacles to getting safe, timely, and informed care. We are working to remove those barriers — and our lobbying has been instrumental in securing NHS funding dedicated to sickle cell improvement. Through focused, sustained action, we have continued to play a key role in transforming services from the inside out, ensuring that change is delivered where it matters most.

HEALTHCARE IMPACTS

Raising the bar for transition care

Our North East London project is setting a new standard for supporting young people as they move from paediatric to adult healthcare, co-designed with those it's for.

Trusted, influential reports

No One's Listening, and *A Matter of Life and Death* reports remain go-to references for clinicians, researchers, and media when discussing sickle cell care and systemic failings.

National recognition for tackling inequalities

One of only two winners of the 2023 NHS Health Inequalities Targeted Call, our Children and Young Person's Peer Mentoring Programme was highlighted as an example of innovation, and the accompanying funding has enabled the programme's expansion into the North West and South Yorkshire this year.

Advocacy where it's needed most

In just eight months, our new Advocacy Link Worker has supported more than 250 sickle cell patients in low-prevalence areas across the East of England, improving access to health and social care.

Early detection, better starts

Our work with the NHS newborn screening programme ensures every positive test result for sickle cell begins a supported, culturally informed journey for families, helping newly diagnosed children get the best start in life.

Healthcare professionals learning from lived experience

127 professionals joined our online session on screening, with feedback showing direct changes in practice after hearing from parents.

Widespread professional reach

Over 500 midwives, health visitors, and other professionals engaged with our screening awareness work through talks, stalls, and webinars.

One of our most-visited resources

Our screening programme page drew more than 20,000 views and 70,000 interactions, making it one of the most popular sections of our website.

Screening awareness beyond newborns

We've raised awareness for anyone wanting to know if they have the sickle cell trait or the condition, particularly in family planning contexts, ensuring this vital information is widely accessible.

Setting Standards of Care

We worked with the Royal College of Nursing to develop a Sickle Cell and Thalassaemia Competency Framework, giving healthcare professionals clear guidance on providing the best possible care. In the first four months after launch, the framework was accessed more than 650 times – a promising start, showing that staff are actively seeking out ways to better serve patients with sickle cell.

Our NHS Engagement Lead (Screening Programme), Iyamide Thomas, discussing our research summary poster at the international ASCAT conference.

LIFE-SAVING ACTION

Working with NHS Blood and Transplant, our Give Blood, Spread Love, England programme is increasing blood donation in Black and Brown communities — an important lifeline for people with sickle cell who rely on regular transfusions. These communities are more likely to have the ‘RO’ blood genotype, which better matches the needs of sickle cell patients and helps reduce serious complications from transfusions.

LIFE-SAVING IMPACTS

- 59 blood donation events reached over 30,000 people.
- From these, enough new donor sign-ups to save or improve the lives of up to 1,800 adults or 3,600 children living with sickle cell.
- Unite for Sickle Cell student programme launched donor networks at universities in Manchester, Bristol, Birmingham, and London.

Students attended a ‘Unite for Sickle Cell’ wellness event at the University of Manchester Students’ Union Freshers Fair in 2024.

Sickle Cell Children and Young Person's Mentoring Programme, expansion to North West England. Mentors Leila Smith (middle), Hafsah Ajimotokan (right) and Oluwabukola Akanni at the Sheffield Patient Education Day delivered by the HCC North East and Yorkshire region, at Sheffield Hallam University.

REACHING PEOPLE WHERE THEY ARE

From hospitals to WhatsApp chats to rugby pitches, we make sure we're present where our community needs us most. This year, we expanded digital engagement, increased our presence in local communities, and provided direct, practical support.

Our advice line remains a vital lifeline — offering tailored guidance and advocacy through 279 calls and 1,000 emails. Enquiries covered health, education, social care, housing, welfare benefits, and more, helping people navigate the daily challenges of living with sickle cell. We also advised professionals in schools, healthcare, and other sectors on how best to support individuals with the condition.

Our nationally recognised Children and Young Person's Peer Mentoring Programme continues to grow, building futures as well as services. Aligned with key NHS reports and strategies, it provides emotional support, practical guidance, and inspiration for young people with sickle cell.

PEOPLE IMPACTS

(PEER MENTORING SCHEME)

- 300+ referrals in London, and this year expanding into Liverpool, Manchester, and Sheffield.
- Participant feedback shows improved confidence, resilience, and wellbeing.
- Featured on **ITV News**, highlighting the challenges faced by young people and the value of mentoring.
- Future Focus sessions offered practical advice on university, apprenticeships, and life after school, broadening our scope of support.

YOUNG VOICES, BIG FUTURES

Young people are a particularly vulnerable part of the sickle cell community — facing distinct challenges that require support tailored to their needs, in their spaces, and in their language. Without that, their health outcomes and opportunities can be undermined.

This year, we've worked with young people to co-create podcasts, collaborate on a theatre production, explore aspirations, and expand our peer mentoring service. From managing their health to pursuing their ambitions, they're proving that sickle cell doesn't define their future — and we're here to help them thrive, not just get by.

Sickle Cell Podcast recording with some of our young Ambassadors.

Our CEO John James OBE, with Theatre Peckham, for a collaborative event in their 'Young, Gifted and Black' series, along with cast members from Netflix's Supacell and key industry figures.

SPEAKING TRUTH TO POWER

We are unapologetic in our advocacy. Sickle cell has been underserved and underfunded for decades, and dismantling those deeply rooted inequalities takes sustained, determined action. We make sure the voices of the sickle cell community are heard in policy, parliamentary, and other decision-making spaces — challenging what doesn't work, and working with those in power to make meaningful change.

Liked by [redacted] and others

sicklecelluk NEW TREATMENT APPROVED FOR SICKLE CELL! We are delighted that NICE has today approved the groundbreaking gene therapy, Exa-cel, or Casgevy, for use through the NHS in people living with sickle cell disorder.

This year, that work delivered a historic result. Our input into the NICE evaluation of a gene therapy treatment for sickle cell contributed to the approval of Casgevy — a groundbreaking treatment based on Nobel Prize-winning technology — for use in the NHS. This landmark decision came after years of campaigning, and was especially significant following the setback of 2024, when two new drugs, Crizanlizumab and Voxelotor (Oxbryta), were withdrawn, leaving the community with just one treatment option and a renewed sense of mistrust in the systems that are meant to serve them.

Our campaigning is always aimed at systemic change. From calling out health inequalities to demanding investment in safe, effective treatments, we will continue to speak truth to power until every person with sickle cell gets the care they deserve.

CEO John James OBE, championing the needs of people living with sickle cell.

COLLABORATIONS THAT MATTER

We work with partners who share our values and our drive for change. Whether it's global brands or grassroots organisations, every collaboration has a shared purpose and delivers real impact. This year, our partnerships have included the UK Thalassaemia Society, Genomics England, the James Lind Alliance, the NHS Race and Health Observatory, and the National Council for Voluntary Organisations, as well as extensive work with NHS England and NHS Blood and Transplant.

These are more than partnerships — they are powerful alliances that move the dial on sickle cell care, awareness, and equity.

COLLABORATION HIGHLIGHTS

Partnership for Change

Joined nine other patient groups, convened by Pfizer, to submit a joint response to the NHS 10-Year Plan consultation.

Supporting people in custody

Worked with HM Prison Service to better support those living with sickle cell in the prison system.

Influencing treatment approvals

With the Anthony Nolan Trust, gathered almost 300 patient responses to a NICE consultation, contributing to the NHS approval of Casgevy gene therapy for severe sickle cell.

Shaping research priorities

With Genomics England, collected over 440 survey responses to help identify the top unanswered research questions for sickle cell disorder, ensuring future research is guided by those most affected.

Our Patron Dame Elizabeth Anionwu, the UK's first specialist sickle cell nurse, and Sickle Cell Society co-founder, opening the Brixton blood donation centre

MEDIA AND CREATIVE POWER

Culture and storytelling are powerful drivers of change — and we use them to connect hearts and minds, spark conversations, and reach new audiences who may never have heard about sickle cell disorder.

From our collaboration with Netflix to a youth-led creative project with Theatre Peckham, and to engaging celebrities and influencers in awareness campaigns, we are building cultural momentum. Through podcasts, media mentions, performances, and digital storytelling, we are making the sickle cell story impossible to ignore.

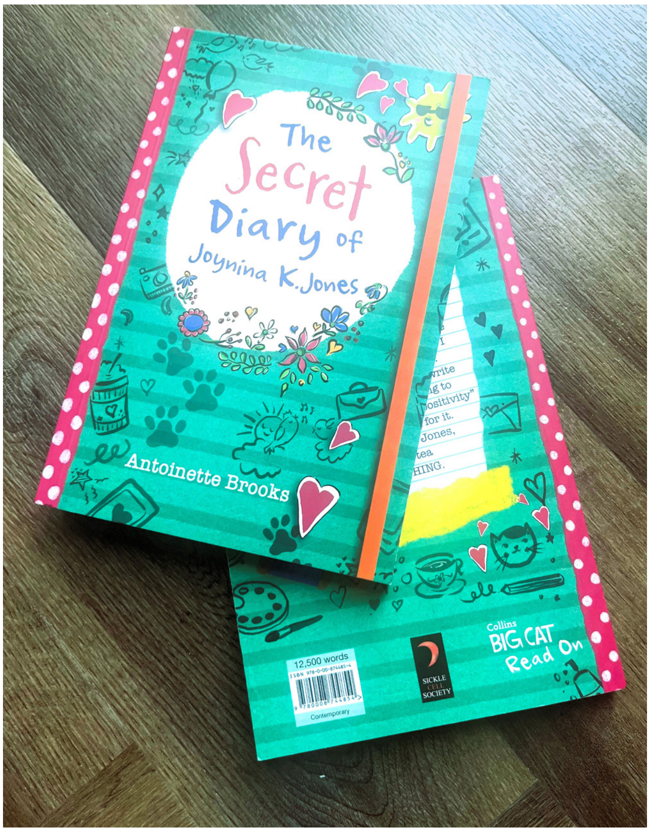
This year's creative and media collaborations included:

- **HarperCollins Publishers** – Raising awareness among young people through a sickle cell story book, distributed through schools.
- **Netflix** – Partnering on communications for the sickle cell–related superhero series Supacell.
- **Theatre Peckham** – Sharing local awareness and education with young adults.
- **University of Westminster** – Exploring new digital communication tools for sickle cell patients.
- **Black Minds Matter** – Highlighting mental health support for young people with sickle cell.

We collaborated with the biggest streaming platform, Netflix, on communications for Supacell, their new superhero drama which centred around a sickle cell storyline. The show went to number one in the Netflix charts worldwide.

Our podcast guests spoke honestly about their lived experience with sickle cell.

In collaboration with HarperCollins Publishers, we supported The Secret Diary of Joynina K Jones — a powerful account of teenage life with sickle cell.



We worked with The Superdrug Edit to feature one of our ambassadors and her mother, celebrating their bond and the importance of family support in sickle cell care. (with kind permission of The Superdrug Edit)

HEALTH STORIES

ASI *(left) and* **NUSIRAT**
Nusirat carries the sickle cell gene and her daughter Asi has sickle cell disorder (SCD) – which happens when the sickle cell gene is inherited from both parents. SCD is particularly common in people from African and Caribbean backgrounds. It affects red blood cells, with symptoms including anaemia and painful episodes called 'crises'.

'Mum's strength is my inspiration'
ASI, 26

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HEALTH STORIES

like MOTHER, *like* DAUGHTER

Inspirational parents and children share how they've helped each other cope with a health issue that affects both of them

NUSIRAT KOLAWOLE IMAM, 53, a support worker, *and* **ASI IMAM, 26, a sickle cell nurse,** *are from south London*

NUSIRAT ♥ 'Growing up in Nigeria, very little was understood about sickle cell. Neither I nor my then husband knew that because we both carried the sickle cell gene, our children were at risk of having sickle cell disorder. My two sons died because of sickle cell complications, and of my three daughters, Asi is one of two with the condition.

'Asi has been in and out of hospital since she was a child. She is often in pain, and on one occasion she needed a life-saving blood exchange transfusion. Despite this, she has never let it hold her back – she decided early on that she wanted to help others as a sickle cell nurse. I'm incredibly proud of her. I've cried so many times, but Asi always puts a smile on my face. We're very close, like sisters, and love travelling and going out for lunch together. We can talk about anything, and she gives me strength. As long as she's OK, I'm OK.'

♥

ASI ♥ 'The way to describe my symptoms is as a horrendous sharp pain, like stabbing needles, anywhere in the body. It's triggered by anything from dehydration to stress, so I have to look after myself. When I don't, Mum has a sixth sense – she'll often call the hospital before I realise I need it!

'The older I get, the more I understand how much Mum has sacrificed to give me and my sisters what we need. She has raised us alone, moved countries to get us better treatment and worked two jobs, doing night shifts to be in hospital with us during the day. If she hadn't, I probably wouldn't be here now. Mum's strength is my inspiration.

'I want to do everything I can to help others and spread awareness. It's so important to know your family health history, and – particularly if you have an African or Caribbean background – to get a genotype test, to tell future partners and educate your children.'

More information: sicklecellsociety.org ➤

Asi and her mum Nusirat enjoy a sister-like closeness and draw strength from each other

Words: Jenny Wood

EXPERTISE YOU CAN TRUST

When the media, researchers, and health leaders need insight on sickle cell, they turn to us. Our work is grounded in lived experience and backed by decades of credibility. We are a trusted voice in the rooms where decisions are made — influencing NHS policy, contributing to national conferences, and shaping the conversation. Our influence is earned, and we use it to secure meaningful change.

> You guys are heroes
>
> - C Burgess

The Sickle Cell Society Team

POWERED BY LIVED EXPERIENCE

Lived experience is at the heart of everything we do. The stories, insight, and leadership of people with sickle cell shape our decisions at every level. Whether developing campaigns, designing services, setting research priorities, or speaking on national stages, we amplify and empower voices that have too often been ignored. This is what makes our work authentic, relevant, and impactful.

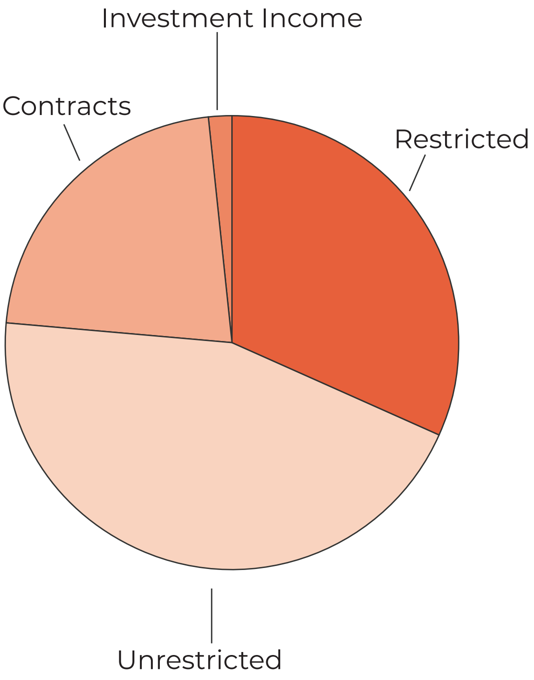
> Your leadership, advocacy and commitment with staff from the Society, other patients and NHS staff have all paid off. Well done John and thank you!
>
> - J Okochi

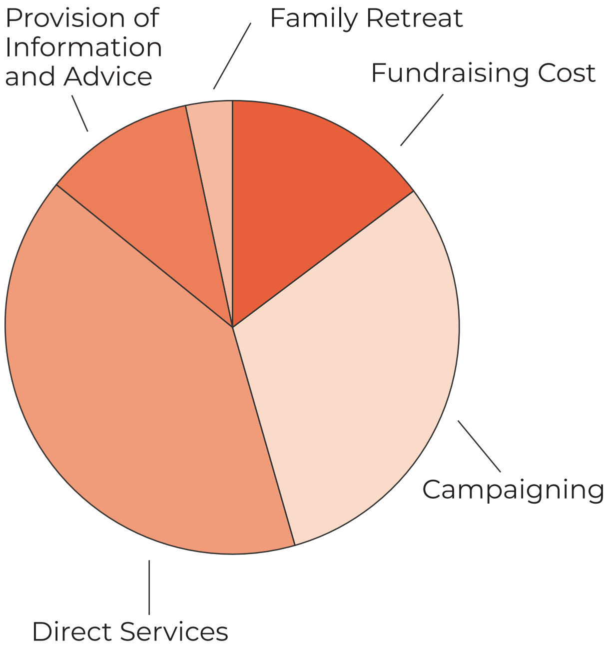
At the COLLABORATE Summit in Prague, we brought the voice of the sickle cell community to the global rare disease stage.

FINANCIAL SUMMARY

Total Income	**£1,426,839**
Restricted	£453,109
Unrestricted	£639,774
Contracts	£310,663
Investment Income	£23,293

Total Expenditure	**£1,106,823**
Fundraising Cost	£165,662
Campaigning	£338,946
Direct Services	£446,648
Provision of Information and Advice	£119,511
Family Retreat	£36,056





Our amazing team of staff and volunteers at our 2024 Family Retreat.

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