

sicklecell



THE NEWSLETTER OF THE SICKLE CELL SOCIETY

SPRING 2020

In this issue:

Highlights from the Gala Ball

New Paediatric Standards

Sickle Cell World Assessment Survey

Plus, so much more...

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COVER
Children's Holiday

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Introduction

Over the last six months, as well as continuing our work as normal, we have also been celebrating our 40th Anniversary. We want to say a huge thank you to our members, supporters, donors and everyone else who has helped us celebrate our 40th Anniversary. It has been wonderful to see people come together in support and celebration and to be able to look back over the past 40 years and see all the hard work people have done to improve sickle cell care in the UK.

Our celebrations reached their peak at our 40th Anniversary Gala Ball; the first Gala Ball we have held in decades. It was a fitting way to celebrate and raise funds and it was great to have so many of our supporters join us. Thank you to everyone who came along to show your support, to the performers who provided entertainment and to the staff and volunteers who helped make it all happen. Looking forward to 2020 and beyond we know that there will be lots to continue celebrating but also many challenges and difficulties which we will need to overcome.

One of the things to celebrate is the possibility of two new drugs becoming available in the UK (subject to NICE and NHS England approval). For a long time, many sickle cell patients have had to rely on just one drug (Hydroxycarbamide/Hydroxyurea). Hopefully, in the near future, two new options (Crizanlizumab and Voxelotor) will become available. As more news develops about these treatments we will be sure to keep you informed.

We are excited to have worked with Public Health England to produce the 3rd edition of 'Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care' which aims to help improve the lives of children and young people living with sickle cell in the UK. We hope that standards and recommendations will prove to be vital support to paediatricians, haematologists, specialist nurses and psychologists but also to parents and carers in insuring the best care for their children.

As you may remember, we have been working with NHS England on the NHS Haemoglobinopathy Review (Sickle Cell Service



Review). The review looked at changes to specialised services for sickle cell, thalassaemia and other rare inherited anaemias. Keep an eye on our website, social media and e-newsletter for updates on the review as we get them.

One of the challenges ahead continues to be around finances. We continue to be in an uncertain economic time which means extra work and care is being taken to ensure the greatest service can be delivered. We are so grateful to our donors and fundraisers who continue to support our work. Their contributions enable us to grow our work, reach more people and plan for the future. You can read about some of those who have helped support us and ways in which you can get involved later in the newsletter.

You may remember that we were involved with the Sickle Cell World Assessment Survey (SWAY) a global survey of sickle cell patients and treating healthcare professionals aimed at understanding the current burden and unmet needs in sickle cell patients. We were able to recruit 200 patients to take part and we are pleased to announce that the results are now in. Findings from more than 2,000 respondents in 16 countries underscore the debilitating and under-reported effects of sickle cell and a pattern of not seeking care despite potentially life-threatening symptoms. You can find out more later on in the newsletter.

The last six months has also been full of celebrations for our patrons. One of our patrons, and founding members, Professor Dame Elizabeth Anionwu, received a Pride of Britain Award. As well as that, Sir Clive Lloyd CBE, Professor Dame Sally Davies DBE, Baroness Dame Floella Benjamin OBE, Rudolph Walker CBE and the Right Reverend Rose Hudson-Wilkin MBE were all awarded honours in the Queen's New Year's Honours. We want to wish our patrons a massive congratulations and thank them for all the support they provide for us and the sickle cell community.

The Hackney and City Mentoring Programme has been a big part of our work over the last few years. The project came to an end in 2018

but we are pleased to say that we have been working with East London Clinical Commissioning Groups (CCGs) across the 7 boroughs about the potential expansion of the City and Hackney Sickle Cell Peer Mentoring Programme to all of East London.

Our annual Children's Holiday is always one of our highlights and this year is no different. We had an excellent time this year taking 30 children and young people with sickle cell away on an adventure packed holiday. The holiday was an opportunity for the children to meet others with sickle cell, learn more about managing their condition and have fun. You can see what they got up to and find out how to get your child's place for 2020 later on in the newsletter.

Raising awareness of sickle cell continues to be a priority for the Sickle Cell Society and over the last six months we have been able to engage in a range of awareness campaigns and events to bring sickle cell into the forefront of the public's minds. From community awareness days and Black History Month events to sharing people's stories and getting involved with health awareness campaigns, we continue to see the need and benefit of providing more information around sickle cell. We want to thank everyone who is involved raising awareness and who continue to support our work.

John James OBE CHIEF EXECUTIVE *and*
Kye Gbangbola CHAIR OF TRUSTEES

New Year's Honours 2020



Rudolph Walker OBE
Awarded CBE



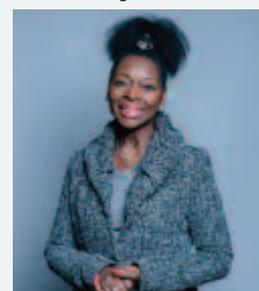
Clive Hubert Lloyd CBE
Awarded Knights Bachelor



**The Right Reverend
Rose Josephine Hudson-Wilkin**
Awarded MBE



**Professor
Dame Sally Davies DBE**
Awarded Dame Grand Cross



**Baroness
Floella Benjamin OBE**
Awarded Damehood

The Sickle Cell Society wants to wish a massive congratulations to our patrons who received honours from the Queen on New Year's Day.

We are so grateful to receive the support that we do from our patrons. Our patrons are notable people who dedicate their time and

resources to raising awareness of our work and support the sickle cell community in a range of different ways.

Five of our patrons were included in the Queen's New Year's Honours 2020 and we want to wish all of them a huge congratulations!

Sickle Cell Society celebra

The Sickle Cell Society celebrated 40 years of working within the sickle cell community with a gala ball in central London.

The Sickle Cell Society, set up in 1979, has spent the last 40 years working to improve the lives of people living with sickle cell disorder and their families. On Saturday 14th September we joined with supporters, service users, patrons and celebrity guests at a glamorous dinner and dance to celebrate the progress that has been made.

Hosted in the Royal National Hotel, the evening opened with a red carpet drinks reception before Chair of Trustees, Kye Gbangbola, opened the event with a powerful

call to action for continued support and donations. The Master of Ceremonies, Chizzy Akudolu (Actress: *Holby City*, *Dead Set*, *Jinx*), then took to the stage to welcome guests and set the celebratory tone of the evening.

The guests then enjoyed a delicious three course meal; many sat at tables hosted by celebrities including: Alison Hammond (Television Personality, TV Presenter on *This Morning*), Rudolph Walker OBE (Actor: *Eastenders*, *The Thin Blue Line*, *King Ralph*), Baroness Floella Benjamin OBE (SCS Patron, Actress, Writer, Campaigner), and Kym Mazelle (1st Lady of House Music, 2X Grammy Nominated Recording Artist).

Chizzy Akudolu then returned to the stage to thank the evening's sponsors and welcome a few supporting politicians including: Dawn Butler MP; Janet Daby MP; Mayor of Brent, Ernest Ezeajughi; Mayor of Camden, Maryam Eslamdoust; and London Assembly Member, Florence Eshalomi.

London rapper, and sickle cell advocate, A Star, then took to the stage to perform his new single, *Hidden Pain*. The song was produced in association with NHS Blood and Transplant and gives a powerful insight into living with sickle cell.

All the guests then sang happy birthday to Sickle Cell Society patrons: Baroness Floella



Chair of Trustees, Kye Gbangbola, opening the Gala Ball



Gala Ball Dance Floor



Cathy Coppinger (former National Programme Manager of the NHS Sickle Cell and Thalassaemia Screening Programme); Mayor of Brent, Ernest Ezeajughi; Mayor of Camden, Maryam Eslamdoust; and John Osborne



Enjoying the drinks reception at the start of the evening



The B Positive Choir

tes 40 Years with Gala Ball

Benjamin OBE and Rudolph Walker OBE. They both shared a few words about why they support the cause and congratulated the Society on 40 years.

The second performer for the evening was Soul/R&B singer and songwriter, Shaila Prospere, who gave a spectacular performance and also donated a few copies of her new album.

Next to the stage was Coronation Street and The Royals actress, Victoria Ekanoye. She gave two brilliant performances including an acapella rendition of Etta James' 'At Last'. She also spoke about her commitment to supporting the sickle cell community.

Founding member and patron, Professor

Dame Elizabeth Anionwu then took to the stage to draw the winning raffle tickets for the many prizes kindly donated by supporters.

A fundraising auction was then held with unique gifts including: a signed Chelsea FC shirt, a signed Arsenal FC Banner, tours with both Lord Boateng and Baroness Benjamin of the Palace of Westminster and a copy of Monopoly signed by Mayor of London, Sadiq Khan.

The Official NHS Blood and Transplant Choir and Britain's Got Talent finalists, B Positive, then took to the stage to give a spectacular performance. Their two songs received a standing ovation and they gave a powerful message about supporting the sickle cell

community by giving blood.

Garfield Robinson of The Voice newspaper then gave a few words and presented the Society with a framed article detailing the history of the Sickle Cell Society. The piece came from a 4-page spread on the Sickle Cell Society in the most recent edition of The Voice. Copies of the newspaper were also donated for the guest's goody-bags.

Chief Executive, John James OBE, was then welcomed to the stage to thank those involved in making the evening happen and to say a few inspiring words about the next 40 years. Chizzy Akudolu then closed the formal part of the evening and opened up the dance floor.



Kym Mazelle and Dame Baroness Floella Benjamin on the Red Carpet



View from the stage of dining guests



Garfield Robinson from the Voice Newspaper making the presentation to John James OBE

Red Carpet Photos

A massive thank you to everyone who came to our 40th Anniversary Gala Ball on Saturday 14th September. We had such an amazing time celebrating with you!

Photos from our red carpet reception are now on sale! If you didn't get a chance to buy them on the day, make sure you get your copy now.

You can look through the photos and buy yours here: bit.ly/redcarpetphotos

The event password is: Hotel

General Photos

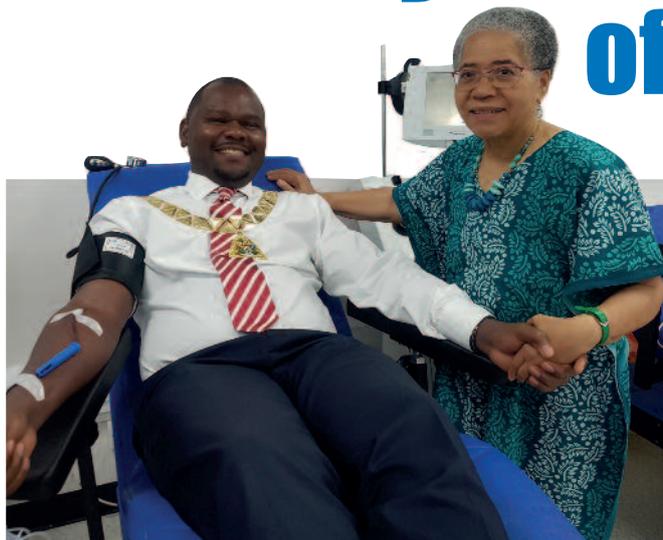
During the evening there were also other photos taken. You can see the gallery of all of those photos from the Gala Ball

www.sicklecellsociety.org/galaballphotos/

Victoria Ekanoye singing 'At Last'

Mayor of Brent's Charity of the Year

UPDATE



Mayor of Brent giving blood with SCS Patron, Professor Dame Elizabeth Anionwu

As you will have read in our previous newsletter, this year we are one of the Mayor of Brent's Charities of the Year. Cllr Ezeajughi became the First Citizen of Brent last May at the Annual Meeting of Brent Council's Mayor Making Ceremony which took place at Brent Civic Centre. At the ceremony he also announced the two charities he would be supporting throughout his year in office: the Sickle Cell Society and the Jason Roberts Foundation.

Since then, the Mayor and his team (alongside all of their normal responsibilities) have been raising money and awareness for both charities.

Windrush Event – On 22nd June, the Mayor of Brent hosted a Windrush Afternoon Gala which featured a Windrush exhibition and three-course Caribbean meal.

Civic Service – We had a great time at the Mayor of Brent's Civic Service Reception at Brent Town Hall on the 23rd July as one of his charities of the year. Our Chief Executive, John James OBE, gave a speech to raise awareness of sickle cell.

Gala Ball – In September, the Mayor attended our 40th Anniversary Gala Ball to show his support and help us celebrate our 40 years as a charity.

Charity Football Match – On Monday 14th October, the Mayor hosted a 7-a-side charity football tournament to raise money and awareness for both of his chosen charities.

Mayor of Brent's Civic Service

Festive Dinner and Dance – On Friday 6th December, we attended the Mayor's Festive Dinner and Dance, enjoying a fun evening of celebration, awareness and fundraising.

New Year's Day Parade – most recently the London Borough of Brent won the first place Prize at the London's New Year's Day Parade (LNYDP) held in central London on the New Year's Day winning £10,000 which will partly go to support our work.

Blood Donation

The Mayor of Brent, Councillor Ernest Ezeajughi, has also donated more than just time in his bid to encourage Brent residents to help save lives.

Rolling up his sleeve during Black History Month, Councillor Ezeajughi



Mayor of Brent Windrush Fundraiser

donated blood to show his support for our campaign to get more people from black communities to register to donate blood. People from black African, black Caribbean and mixed heritage backgrounds are more likely to have the rare Ro blood subtype that is vital for sickle cell patients. The NHS needs around 40,000 new black blood donors to register, to help provide blood for the thousands of people with sickle cell who need regular transfusions.

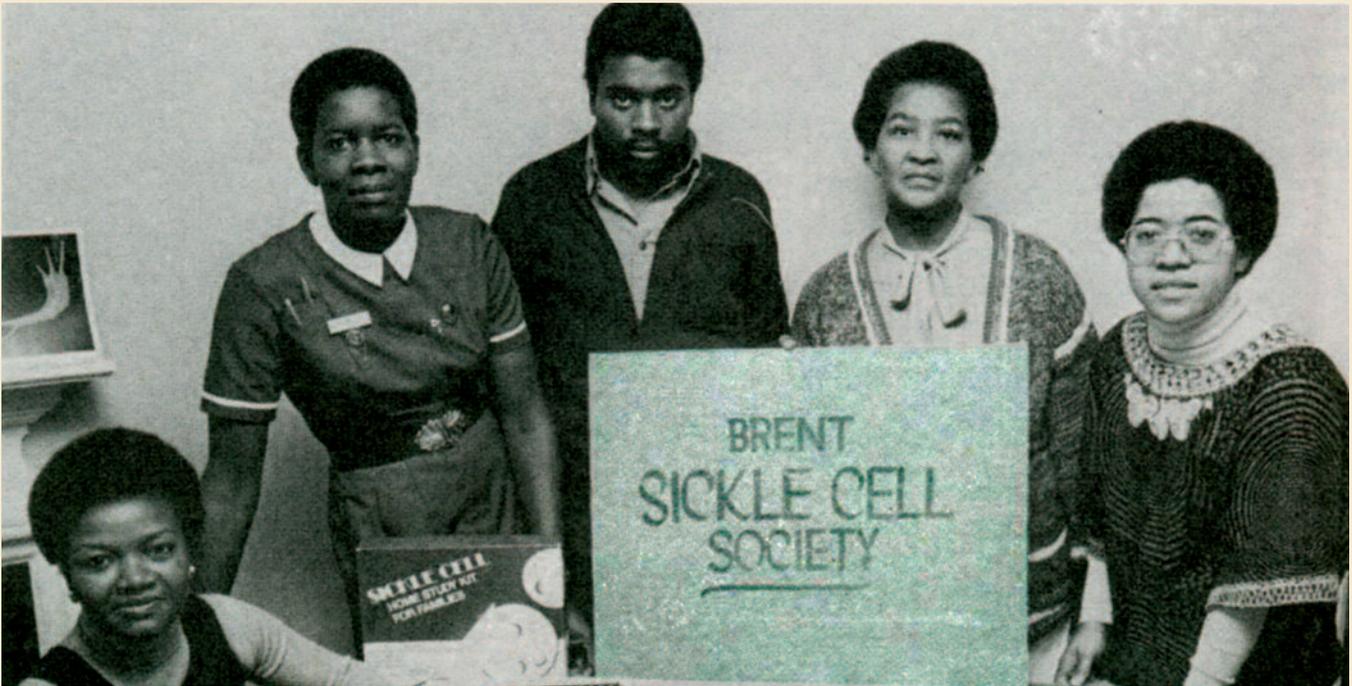
The Mayor of Brent said:

"I chose the Sickle Cell Society as one of my mayoral charities as they do amazing work supporting people who live with sickle cell. I'm passionate about doing as much as I can to encourage all those who are able to, to donate blood. Brent is an extremely diverse borough and there is likely to be a large number of people who live with sickle cell, or who know people who do. So I am asking all the residents in the borough, especially those with African or Caribbean heritage, to do something amazing for their community, and register to give blood."

Professor Dame Elizabeth Anionwu, Patron of the Sickle Cell Society said: *"There is a need for more black people to come and donate blood. The impact of that blood for those affected by sickle cell is absolutely incredible."*

You can watch the full video of the Mayor giving blood and discussing sickle cell with Dame Anionwu here: <http://bit.ly/mayor-donates-blood>





Our Journey, Our Story

Our Journey, Our Story is the Sickle Cell Society's new project funded by the Heritage Lottery Fund. Through oral histories we will explore the history and memory of sickle cell disease in the UK since the Windrush's arrival. SCD disproportionately affects people of black African and Caribbean heritage and is now the UK's fastest-growing genetic condition – changes over the last 70 years have been immense. This project is necessary and crucial. Although SCD has been medically recognised as a health condition for over a century, awareness of it remains relatively low and people with SCD are still facing stigma.

This project will look at:

- The issues faced by people with SCD (and carriers of the trait) and their families
- How campaigning and lobbying has dramatically increased awareness and understanding of SCD, improved standards of care, increased diagnosis and informed research and treatment
- The role of the NHS, patient support groups and the Sickle Cell Society
- Recognising the individuals to whom we owe thanks for their tireless hard work and commitment to the cause.

We will target participant groups in London and the rest of the UK (where SCD prevalence is high),

engaging a much wider audience in public events. Over a few months, we will deliver:

- A film
- Research/evidence-gathering
- Establishment of a Sickle Cell Society archive
- Heritage workshops engaging young people and the over 50s affected by SCD
- Oral histories obtained from campaigners, pioneers, patients, and other prominent individuals
- An exhibition accompanied by public events.

Whether you are patient, a carer, a family member of a sickle cell patient, a campaigner, medical professional and you want to share your story, your archives or simply you want to know more about the project contact Alinta Sara (alinta.sara@sicklecellsociety.org)

Leaving a Gift

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

We would love for you to get in touch if you are interested in leaving a gift or if you have questions about how it works and how we will use your money. You can contact us using the



details below:

By Phone: **020 8961 7795**

By Email:

ainhoa.munoz@sicklecellsociety.org

By Post: **54 Station Road, London, NW10 4U**

Or by visiting:

www.sicklecellsociety.org/leaving-a-gift/

We want to say a massive thank you to all who choose to leave a gift in their will to support our work. We know that it is an important decision to make and we greatly appreciate that you have chosen to support us.

If you do decide to leave a gift to support our work, then we would love to know about it. That way we can keep you updated with the work we are doing.

Pride of Britain Award

Sickle Cell Society patron wins Pride of Britain Award



Dame Elizabeth Anionwu receives Pride Of Britain 2019 Lifetime Achievement award with Janet Jackson at the 20th Pride of Britain 2019

One of the Sickle Cell Society's patrons and founding members, Professor Dame Elizabeth Anionwu, was awarded a Lifetime Achievement Award at the Daily Mirror Pride of Britain Awards.

The Mirror's Pride of Britain Awards in partnership with TSB, celebrate the achievements of truly remarkable people who make our world a better place. Screened on ITV in November, it is the

biggest awards show of its kind on British TV. Winners are nominated by the public for categories including Outstanding Bravery, Child of Courage, Special Recognition and the Lifetime Achievement award.

Dame Elizabeth was awarded the Lifetime Achievement Award for her dedication to nursing and the care of people living with sickle cell. The award highlighted the struggles Elizabeth faced in her early life and the kindness of nurses who treated her eczema and inspired her to follow in their footsteps.

Dame Elizabeth has had a 50-year career as a nurse and in 1979 (alongside Dr Misha Brozovic) she set up the UK's first sickle cell and thalassaemia screening and counselling



Dr Misha Brozovic, Consultant Haematologist at Central Middlesex Hospital & Elizabeth Anionwu 1977



Dame Elizabeth Anionwu with friends and family at the Pride of Britain Awards

centre in Brent, North West London. In that same year she was also one of the founding members of the Sickle Cell Society.

All this year, the Sickle Cell Society has been celebrating 40 years of working within the sickle cell community, and looking forward to counting this work for the next 40 years and beyond. Dame Elizabeth continues her support as patron of the Society and as Chair of the Fundraising Working Group.

Dame Elizabeth attended the Pride of Britain awards with her daughter; granddaughter; SCS Chief Executive, John James OBE; and other friends and family. The awards were held on Monday 28th October at Grosvenor House in London.

The 2019 Pride of Britain Awards were screened on ITV on Tuesday 5th November at 8pm.

Sickle Cell Awareness Day (Watford)

On Monday 14th October, our Chief Executive, John James OBE, attended the Sickle Cell Awareness Day in Watford at Watford General Hospital. The Awareness event was hosted by the Watford Sickle Cell and Thalassaemia Support Group, Watford African Caribbean Association and the BME Network of the local NHS Trust.

The day included talks from a SCD

children's nurse specialist; Phil Daly, contributions from Assistant Nursing Director and the Chief Financial Officer of the local NHS Trust and John himself. There was also a panel

discussion Q&A and a chance for attendees to network together. It was a great event providing important information and awareness in Watford.



40 Day Challenge

In celebration of 40 years of the Sickle Cell Society, the Self Over Sickle team have curated 40 daily challenges for you to try and share with us!

The initial challenge ran from the 1st November – 10th December on Instagram but the challenge can be taken at any time.

From showing your outfit of the day (#OOTD) and how you're keeping warm in cold weather to lip-syncing to your favourite feel good song, the Self Over Sickle challenge has no limits. We want to remind sickle cell warriors, carers and advocates everywhere that you still have the power. No challenge is too great, especially when we work together. Find all 40 challenges on Instagram @SelfOverSickle or by visiting: www.sicklecellsociety.org/sos-40-day-challenge/

So what are you waiting for? CONQUER TODAY'S CHALLENGE NOW.

Presentation to the Health Improvement Alliance Europe

On the 25th September, our Chief Executive, John James OBE and our Patient Education and Training Lead, Siann Millanaise, gave a presentation to the Health Improvement Alliance Europe (HIAE) at the King's Fund in Marylebone. This was an excellent opportunity for senior leaders from HIAE to learn more about sickle cell and the great work of the Society.

The Institute for Healthcare Improvement HIAE is a coalition of 80 progressive leaders from the UK and Europe, who are united for change, driven by collaboration, and focused on achieving health and health care results. Members of the HIAE (including the King's Fund) get together a couple of times a year at a different country/city host. In September, The King's Fund and The Health Foundation jointly hosted members across two days.

The Sickle Cell Society was invited to speak at the London meeting on the Society's role (and the role of other voluntary and community sector organisations) in the wider health and care system and in the sickle cell community. John and Siann also spoke about how the Sickle Cell Society have worked with national government to influence policy development.



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.

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

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/



UPDATE

SICKLE CELL WORLD ASSESSMENT SURVEY

The Sickle Cell World Assessment Survey (SWAY)

An international, multicountry, cross-sectional survey assessing the impact of sickle cell disease (SCD) on the daily life of patients, including:



Physical Symptoms



Emotional Well-being

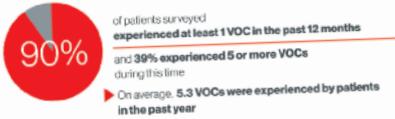


Economic Burden

SWAY sickle cell world assessment survey

Vaso-occlusive crises (VOCs) and Hospitalizations¹

Patients who completed the survey reported substantially higher numbers of VOCs than current published data, **suggesting VOCs are underreported**



People living with sickle cell disease often don't seek care despite symptoms and complications



Of more than 11,000 VOCs reported by survey respondents, **33%** resulted in hospitalization while nearly one-quarter were managed at home

When asked why they did not seek medical assistance for VOCs:



39% said the main reason they chose to manage their VOCs at home was due to a previous poor experience at the ER or hospital



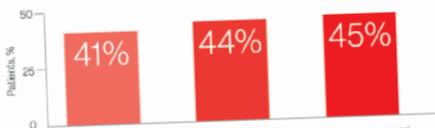
26% said they didn't seek assistance due to a perception that health care providers do not understand SCD



19% said their VOCs are treated at home because the pain can be too severe to leave home

Burden Beyond Physical²

Sickle cell disease has a **substantial impact on patients' emotional well-being and daily life**



Economic Impact²

Sickle cell disease **impacts patients' ability to work and/or complete their education**



Surveyed patients, on average, report **over 1 day of missed work every week** (8.3 hours over 7 days) because of their disease

References: 1. Chubb, J. et al. "An International Survey of the Burden of Sickle Cell Disease in Patients with Sickle Cell Disease." *Journal of Clinical Investigation*. 2019. 2. "Sickle Cell Disease: A Global Health Challenge." *World Health Organization*. 2018. 3. "Sickle Cell Disease: A Global Health Challenge." *World Health Organization*. 2018. 4. "Sickle Cell Disease: A Global Health Challenge." *World Health Organization*. 2018.

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Findings from more than 2,000 respondents in 16 countries underscore the debilitating and under-reported effects of sickle cell disease and a pattern of not seeking care despite potentially life-threatening symptoms [1].

Patients reported on average more than 5 vaso-occlusive crises (VOCs) per year with serious impact on their quality of life (QoL), including emotional well-being and daily life, as well as ability to work and complete education [1,2].

Sickle Cell World Assessment Survey (SWAY),



Ify Osunkwo, MD, MPH

one of world's largest sickle cell disease surveys, supported by international steering committee of medical experts and patient advocates.

"We see sickle cell as a painful disease, but too often we don't translate how that pain affects the lives of our patients – can they go to school, can they work, can they enjoy their families? These are things many of us take for granted," said Ifeyinwa Osunkwo, MD, MPH, Founder and Director, Sickle Cell Disease Enterprise, Levine Cancer Institute, Atrium Health and co-chair of the SWAY Steering Committee. "Perhaps health care providers don't always see the impact of sickle cell disease in that light. Now, with the results of this worldwide sickle cell survey, we have a clearer picture of the toll it takes on millions of people around the world." – Basel, December 9, 2019

The Sickle Cell World Assessment Survey (SWAY) collected insights from more than 2,100 patients (200 of which came from the Sickle Cell Society) and 300 health care

providers to evaluate the impact of the disease on patients and families and help inform the management of this life-long condition. Results were presented at the 2019 American Society of Hematology (ASH) Annual Meeting.

Results showed substantially higher numbers of vaso-occlusive crises (VOCs) than current published data suggesting VOCs are highly underreported and many are experienced at home:

- On average, patients experienced more than 5 VOCs each year, [1] and
- More than 90% of patients surveyed experienced at least one VOC in the past 12 months [1]
- Of the more than 11,000 VOCs reported, nearly one quarter were managed at home [1]

Considered the clinical hallmark of the disease, VOCs are unpredictable, severe events associated with life-threatening complications. [3] They are the main reason why sickle cell disease patients go to the emergency room or are admitted to the hospital. [4] However, despite the serious risks, nearly one quarter of respondents said they avoid seeking medical assistance, citing previous poor hospital



John James OBE

experiences (39%), perception that health care providers do not understand sickle cell disease (26%), or their pain is too severe to leave home (19%). [1]

"Hearing first-hand from those living with sickle cell disease is incredibly important to shaping how we address their concerns," said John James OBE, Chief Executive, Sickle Cell

Society. "With these new insights, we can improve how we manage this serious disease and help improve quality of life for these individuals."

Results also showed that sickle cell disease has a high impact on patients' ability to work and complete their education:

- Over half said they believe their income would be higher if they didn't have the disease [2]
- More than half (53%) report they have reduced hours at work because of their disease [2]
- More than 50% reported sickle cell disease has had a high impact on their achievement at school [2]

"At Novartis, we are pursuing collaborative research efforts to broaden our understanding of sickle cell disease beyond just its devastating physical symptoms," said Andrew Cavey, Global Program Head, Benign Hematology, Novartis.

"On behalf of a coalition of involved organizations and individuals, we were pleased to share compelling new data from one of the world's largest sickle cell disease surveys that uncover the real-world impact of this condition on those touched by it."

You can find out more about the SWAY Survey, Novartis, disclaimers and the full SWAY Steering Committee Members list here:

www.sicklecellsociety.org/globalsurvey/

References

- 1 Osunkwo I, Andemariam B, Inusa B, et al. Management Strategies and Satisfaction Levels in Patients With Sickle Cell Disease: Interim Results From the International Sickle Cell World Assessment Survey (SWAY). Poster presented at: The American Society of Hematology Annual Meeting; December 7-10, 2019; Orlando, FL.
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Global's Make Some Noise



As you will remember from our Autumn newsletter and on social media, the Sickle Cell Society is one of Global's Make Some Noise charities of the year.

Global's Make Some Noise funds and empowers small charities like us, helping disadvantaged children, young people and their families across the UK. You will most likely know Global as the media and entertainment group, home to some of the UK's biggest radio brands including Heart, Capital, Classic FM, Smooth, LBC, Radio X, Capital XTRA and Gold.

On Friday October 11th we went to



Miai at Heart FM

Global's head office in Leicester Square to cheer on radio presenter Jamie Theakston as he completed his fundraising Bike Britain Challenge. The challenge was one of many that presenters and staff were doing to raise money for us and the other charities.

We were also given the opportunity to have a service user speak on Capital FM and Heart FM about their experience of living with sickle cell. Miai (aged 9) gave a brilliant interview on the radio and was also given the opportunity with her mum and our trustee, Philip, to tour the Global studios.

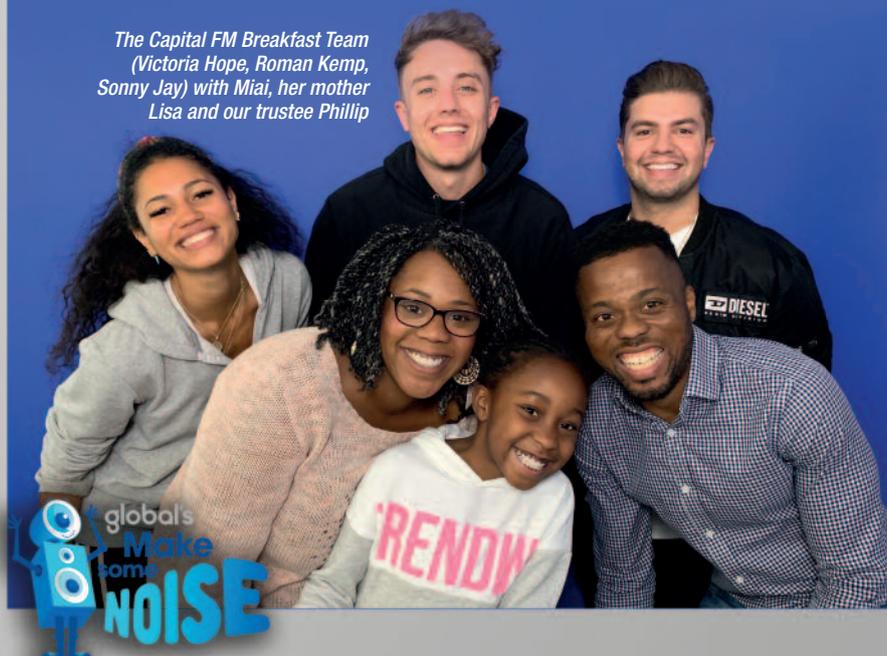
You can listen to her interview on our YouTube Channel.

So far Global's Make Some Noise has raised over £4Million for the 32 charities they are supporting this year.



SCS staff Ainhoa, Siann and Matthew at the Bike Britain finish line at Leicester Square

The Capital FM Breakfast Team (Victoria Hope, Roman Kemp, Sonny Jay) with Miai, her mother Lisa and our trustee Phillip



My Lifetime Sickle Cell Journey

Basil Nigel Bramble

I was born on the 4th April 1958 with sickle cell anaemia. At the age of 18 months I was admitted to hospital, my parents were extremely worried, as parents would be. Mum told me at the age of 13 "the doctors told me and your father you might not make it till the age of ten". I suppose in the 1960s not many doctors or people knew about sickle cell anaemia.

I spent most of my childhood in and out of The Queen Elizabeth Children's Hospital in East London. Twice (at the ages of 10 and 12) the hospital sent me to Banstead in Surrey to convalesce which was for a couple of months each time which meant that I had to miss school. Every Sunday Mum had to catch the coach to visit me in Banstead.

When I left school, I told my family, my school friends and myself that it would be hard for me to get a job because of my illness. That was in 1974. By the grace of God I was offered my first interview. I got there early and was very nervous, I'm sure you know what I'm talking about. It was a Photographic Studio; there was a very well known photographer in the interview. I said "I suffer from sickle cell anaemia" and I was asked "what is that?" Remember in 1974 not many people knew about sickle cell so I said to Lez "lets say



Basil having an Exchange Blood Transfusion at Royal London

I'm anaemic". I left the interview and went home. After a few hours the telephone rang and it was Lez in the office, I was offered the job; it was one of the happiest days of my life.

After spending so much time in the hospital as a child and missing a lot of school it was a great feeling to finally get out in the real world as a man and get my first job. I worked there for a couple of years learning my trade as a Photographic Printer Assistant, Photographer and Messenger.

I managed to get three jobs after my first job, including starting out on my own as a commercial printer. It was a challenge, hard work, but I enjoyed being my own boss. After just over a year my business folded, but it was a good experience.

My final job was working for an Investment Bank. This involved doing shifts which I had never done before, it was very busy but the company gave me so much support. I had a fair few sickle cell crises and bleeds in my eyes. I had been working there for just over 10 years and my manager came to the hospital with me to speak to my consultant. He said "we

know Nigel Basil is having a hard time lately but we would like to keep him as one of the staff". My doctor/consultant asked if they would cut my days down, which they did.

After my eye operation I decided to become a volunteer for Moorfields Eye Hospital. My colleagues at work would give up some weekends to help raise money. We played football and snooker tournaments and my employer let me take time out to help out at the Moorfields. Ten years ago I was rewarded for the work I do at Moorfields so I had to go to the House of Lords. I took my father with me, he was so proud. It was really lovely we had tea there. I met volunteers from different places who were also receiving awards. I have two certificates in my bedroom for ten and fifteen years so I am looking forward to receiving one for twenty years.

I worked at the Investment Bank for 23 years before I had to retire at the young age of 53 due to ill health. Retirement was very hard for me. I had been working from the age of 16 and



Basil at work Morgan Stanley 2008

when I was hospitalised, all I thought about was getting back to work, it kind of gave me strength. Having to claim benefits, something I never done before, was a shock and I was given a hard time, it even tipped me to the edge of depression.

In December 2015, I was admitted to intensive care at the Royal London Hospital where I spent 6 weeks. I had my Christmas and New Year in hospital and I was out for a few weeks but then back in again in February 2016 and back again in April 2016. Not too long after this, I was feeling a lot better so I started volunteering at Moorfields Eye Hospital again. I even went out partying to various venues I go to now and again it was good up until I had another sickle cell crisis in October 2016. I went back into hospital as I was getting a lot



Exhibition: The Colour of Pain

Imperial College London's Centre for Languages, Culture and Communication presented a multi-media exhibition with works by several different artists exploring the experience of sickle cell. The exhibition took place over November and December in the Gallery of the Centre for Languages, Culture and Communication.

Multi-media works by several different artists explored the experience of sickle cell disorder, a condition which millions of people suffer from and which is still largely not understood by much of the population. Pain, fatigue, even death can result from the genetically transmitted disorder and yet so many suffer without the comfort of empathy.

To mark the opening of the exhibition, the

Centre held a seminar by Dr Frederic Piel and our Chief Executive, John James OBE, who spoke about different aspects of the disorder.

Want to get a taste of the exhibition?

Check out our website

(<https://www.sicklecellsociety.org/colourofpain/>) to watch, Trance, a video which has been created as part of the exhibition.



of sickle cell pains and lots of different pains as well which I thought was really strange. After I spoke to the doctors they decided to give me a CT scan. I was a little bit worried but didn't worry about it too much. After about a week I got a call from the hospital to say they had seen something on my scan and would like me to come in. They showed me the scan and said that we're not sure what it was it might be something or it might not be anything.

At the age of 58, they decided to do a biopsy and made an appointment for the 28th November 2016 so I didn't think it was anything too serious. I had the biopsy in the first week of November and when I didn't hear anything after a few weeks I thought it must be OK. Unfortunately, when I went back in on the 28th they said it was a tumour and it had to be removed. I felt like I had been hit by a bus; I felt so down at this time. A month went by and it came to Christmas, I was feeling fine even though I had my worrying times. I was around my family and I was feeling really positive I think that did me the world of good.

I also had to have my spleen removed and my first appointment was the 28th of December 2016. I had to have three jabs for that, see the anaesthetist and pre-op. I went to see the anaesthetist with my dad and I told him I was a bit concerned and had even told my

friend that I wasn't sure if I could go through with it. He said to be positive and as time went by I was having lots of tests and scans because of my sickle cell.

I saw my surgeon about ten days before my operation and he said he was certain the

operation would go well even though I have sickle cell. So I had my exchange blood transfusions the next week which was eight pints in and eight pints out but I was feeling really positive as when I went to the ward to have the transfusions I had started to gain some weight. I was looking forward to the 16th January to go into hospital to have my operation on January 17th 2017.

The day after the operation the surgeons came to do their rounds and they shook my hand and hugged me, telling me that I was very strong and doing really well. It just goes to show that at 58 with sickle cell I managed to get through a major operation. As you can see in the pictures of me I'm back to good form.

In March 2018 I received my twenty years Certificate volunteering at Moorfields Eye Hospital. And in the City of London I received a Stars Award for long service for my volunteering at Moorfields Eye Hospital. Also since retirement I was asked to train in mental health and have volunteered for ELFT.

This goes to show that you can try to have a career like I did and I managed to work for 40 years! I had to give up work due to ill health but I have been volunteering for the last 21 years. Never say you can't do anything, at least try. You really will feel better for doing so.

Basil Nigel Bramble



*Basil Volunteering at Moorfields Eye Hospital
Volunteers Week 2019*

Ways to Fundraise



If you want to raise money for sickle cell but are not sure how, then we have a whole range of useful tools and platforms to help you out.

Day-to-Day Fundraising

If you live a busy life you may not feel you have time to fundraise. Fortunately, there are a few tools which you can use to raise money day-to-day.

AmazonSmile – Shop on Amazon? Then check out AmazonSmile. AmazonSmile is the same Amazon you know; same products, same prices, same service but Amazon donates 0.5% of the net purchase price (excluding VAT, returns and shipping fees) for everything you buy.

To set up visit smile.amazon.co.uk and choose the Sickle Cell Society or via the app (**turn it on in Settings > Amazon Smile**)

easyfundraising – If you shop online at a range of stores then check out easyfundraising. When you use easyfundraising to shop with any of 4,000 retailers, the retailer makes a small donation to say thank you and easyfundraising

sends those free funds to us.

You can start using easyfundraising by signing up through the app or website: www.easyfundraising.org.uk/causes/sickle-cellsociety/

Payroll Giving – If you want a hassle free way to donate then try Payroll Giving. Payroll Giving is a regular donation which is taken directly from your salary. It is simple but also tax effective because your donation gets deducted before you pay the taxman. For example, if you donate £5, the cost to you in your take-home pay is £4 and the taxman pays the rest.

Find out more here at our website: www.sicklecellsociety.org/donate/

SPONSORSHIP EVENTS AND SPECIAL OCCASIONS

Facebook Fundraisers – If you have a birthday coming up then why not set up a Facebook Fundraiser? Facebook Fundraisers are an easy way to raise money by encouraging friends and family to wish you a happy birthday by donating to a charity you support.

You can set up your Facebook Fundraiser all through the Facebook app or on the website: www.facebook.com/fund/SickleCellUK/

JustGiving – From sponsored runs to pages in memory of loved ones, JustGiving is the perfect tool to fundraise. You can set your own targets, customise your page and include your own photos. Plus, each page is directly linked to us so everyone donating knows where the money is going.

Set up your own fundraiser at: www.justgiving.com/sicklecellsociety

Whatever way you choose to fundraise we want to say a massive THANK YOU. We rely on your kind support to keep doing the work we do. Every fundraiser allows us to reach more people, run more activities, and improve the lives of those living with sickle cell.

If you do set up a fundraiser we want to hear from you! Letting us know about your fundraiser helps us plan for the future and enables us to best support you. Please let us know by emailing our Fundraising Officer at: ainhoa.munoz@sicklecellsociety.org

Sickle Cell Society at Google Event

We were excited to be invited to host a stall and provide educational flyers at the Black History Month Sickle Cell Awareness Event hosted by Google and Facebook on Monday 21st October.

The event saw talks from sickle cell nurse Esther Akinwunmi, real stories from Esther Gbogboade and Precious Gaza (who sent in a video from hospital as she had a crisis just before the event), presentations

from Olaolu Baikie and UASCD president, Roseline Mbotchak.

There was also an informative Q&A Panel including: Chris Abdullahi (Sound of Sickle), Danielle Oreoluwa (TED Talk speaker), Vashti-iona Beckford (Wall of Comedy), Esther Akinwumi (NHS Nurse), and Fauzia Van De Leeuw (DEI Staffing Partner).

It was a brilliant evening of awareness and networking and we hope to see many more.



New Standards for Clinical Care of Children with Sickle Cell

The Sickle Cell Society, in partnership with Public Health England have recently produced the 3rd edition of 'Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care' which aims to help improve the lives of children and young people living with sickle cell in the UK.

Approximately 15,000 people in the UK live with sickle cell (a life-threatening, inherited blood condition) with around 270 babies born



Rt. Hon. Pat McFadden MP

each year with the condition. 1 in 76 babies born in the UK are 'carriers' or trait (i.e. they do not have the condition but have one copy of the recessive sickle cell gene). The new recommendations are an update of the 2nd edition published in 2010 and have been written to support paediatricians, haematologists, specialist nurses and psychologists to ensure that children get the best possible care and clinical outcomes. It will provide a useful overview for parents to see if services and healthcare are available in the area where they live and to know what they can expect. This edition has also added in measurable standards to enable hospital trusts, commissioning authorities and peer review services to see how well different hospitals are performing.

The new edition reflects what has been learned from peer reviews of hospital trusts conducted nationally during 2010-2011 and 2014-2016 which looked at what services were being delivered, measured against quality indicators and standards and also includes the recent guidance from NHS England on

specialist services and networks. It updates clinical recommendations in several key areas and emphasises the importance of collecting data and measuring outcomes against robust standards.

Rt. Hon. Pat McFadden MP, Chair of the All Party Parliamentary Group on Sickle Cell and Thalassaemia stated: "I welcome the publication of these updated standards for sickle cell care among children and thank the Sickle Cell Society and everyone involved in the preparation of this document. I very much hope these standards will be used by health professionals and NHS trusts to improve sickle cell care for children and to ensure consistency of treatment around the country. Sickle cell is a very challenging condition for families to cope with and the dissemination of good standards in care is really important".

Professor Baba Inusa, Lead Consultant Paediatric Sickle Cell and Thalassaemia, Evelina London Children's Hospital added:

"The 3rd edition of the standards and recommendations for Clinical Care (Sickle cell disease in childhood) published November, 2019 is a very useful document that was written with great care that sets the scene for further research to support the development of evidence-based data for the benefit of patients. It will serve as impetus for clinicians, a goal to achieve for the benefit of our patients. The executive summary provides a well laid out plan for audit of service provision. I recommend this highly as a tool that other countries may wish to access in building their own standards of care".

Ade and Caroline parents from East Sussex remarked:

"As parents of two children with sickle cell living in a part of the UK where the condition is not common, we welcome the publication of these updated Paediatric Standards which will help guide health professionals deliver the best

possible healthcare around the country. It is another big leap in the knowledge base of treating sickle cell, bridging the gap between the patients, parents (carers), and professionals all in partnership spirit for the betterment and improvements in caring for the patient population. With this in mind and in hand, no one need fear their quality of care anywhere in the UK. We plead and say, USE IT".

This third edition of the clinical recommendations and standards for the care of children with sickle cell has been published as a result of collaboration between clinicians, parents and carers, the Sickle Cell Society and UK Forum on Haemoglobin Disorders, together with the NHS Sickle Cell and Thalassaemia Screening Programme and Public Health England.

The standards are now free to download from the Sickle Cell Society's website:

www.sicklecellsociety.org/paediatricstandards/

Hard copies will also be printed and officially launched.



CHILDREN'S HOLIDAY

by Grace Adejuwon and Jessica Boatright

From the 10th to 14th August we took 30 children with sickle cell on an adventure holiday to Condoover Hall. Alongside learning about their sickle cell, the children experienced activities such as lazer conquest, high ropes, caving and archery, as well as evening activities such as a talent show and disco. The children, who were split into three teams based on age group again, slept in shared dormitory rooms split by gender with bunk beds to give a real 'summer camp' feel to their experience.

The children reported that "this was the best holiday ever" and particularly learnt lots about sickle cell and how they "can do anything they believe" despite their condition. They told us they learned confidence, perseverance and lots of practical physical skills. Their favourite parts were the campfire, Lazer Conquest, Ariel Trek and making lots of new friends.

The volunteers were great! A mixture of experienced and new volunteers made up the teams, providing lots of encouragement and positive energy which helped the children feel confident, supported and safe during the holiday.

The parents were absolutely thrilled with how the holiday went. In their feedback they reported that their children had grown in confidence and they were especially pleased with the knowledge that their children had gained about sickle cell. All commented that communication had been particularly good and almost all said that their child had made new friends. The WhatsApp group was enjoyed this year too!

The holiday on the whole in 2019 went very smoothly and was, on the whole, a complete success.

Children's Holiday 2020

The Sickle Cell Society is excited to announce that applications are now open for the 2020 Children's Holiday!

Held on the 16th-20th August 2020 at Academy St Albans, the SCS Children's Holiday is an exciting few days of activities and fun for children living with sickle cell aged 8-15.

The trip is FREE for children to attend (this includes all accommodation, food and a whole host of exciting activities). Transport will be provided from Nottingham at no extra cost and the venue is a 20-minute train ride (plus a short bus) from London.

There will be experienced doctors and nurses to provide all medical care during the week – your child will be in very safe hands.

Find out more and register your child at: tinyurl.com/scs-holiday-2020

Deadline for Applications: 1st April 2020

Please note that all children who attend the holiday must have sickle cell disorder.



"My favourite part of camp was making friends and learning about other people's experiences" – Camper





“I learnt that we are not alone with our condition and it is really easy to meet people who have sickle cell” – Camper



“I had an excellent time and will absolutely be volunteering next year. Fantastic experience overall” – Volunteer



“Huge Thank you. I got the 1st break in 9 years. I wasn't stressed either because I knew she would be taken care of” – Parent

South London Gives



Viv and Bola Signing People Up to Give Blood

South London Gives is the Sickle Cell Society's blood donation awareness project. We actively engage with individuals and communities from African and Caribbean backgrounds and:

- Raise awareness of the need for ethnically matched blood to treat people with sickle cell disease
- Breakdown some of the myths and fears that exist around blood donation
- Explain what happens when you give blood, and
- Sign people up to the blood donation register

South London Gives is now in the second year of delivering this pilot project which is funded by NHS Blood and Transplant (NHSBT). The project is trialling a Community Organising approach where a team of trained Community Advocate volunteers use their networks of family, friends, neighbours, work colleagues, churches and leisure interests to highlight the importance of blood donation and encourage others to share the message too, gradually sparking more and more people to get involved and advocate for change.

Blood donation, and ensuring that there is a sufficient amount of ethnically matched blood available, is essential for the treatment of people with severe sickle cell disease. Receiving regular blood donations can help prevent or relieve some of the symptoms of sickle cell including extreme pain, life threatening infections and loss of vision. Ethnically matched blood is needed as it is less likely to be rejected by people having frequent blood transfusions.

In our first year, South London Gives recruited a team of dedicated volunteers. We travelled far and wide giving presentations in churches, work places, colleges and community organisations, we registered hundreds of new donors and talked to more

than 1000 people. We heard their views about blood donation and while some were not aware of the need for ethnically matched blood, most knew that many more black and mixed race donors are needed, however, some had concerns about what was involved, how long it would take and the safety of the process.

Our trained Community Advocates are able to address these common concerns and wherever possible, put peoples' minds at rest, by:

- Sharing the facts of blood donation to replace the myths
- Explaining the positive impact blood donation has on peoples' quality of life, and



Michelle Raising Awareness at HMRC

Bola Community Advocate and blood donor recipient

I am a mum of 2 and I suffer from severe sickle cell disease. However, thank God, my health has improved greatly since embarking on the Exchange Blood Transfusion (EBT) procedure. This is when most of my sickled red blood cells are exchanged with healthy cells from donated blood. I have this treatment every 6-8 weeks and it has changed my life. I have not had a crisis since I started this treatment 3 years ago. Blood transfusions have been the most effective treatment for my illness over the years, so it is important for me to campaign for more black people to give blood so people like myself continue with their treatment.

Through volunteering with South London



Gives (SLG) I get to 'give back' and help encourage others who suffer from SCD. Before getting involved with SLG I hadn't spoken publically about having sickle cell disease. I did this for the first time at my own church, House of Praise, in South London. I am very well-known and involved in the church, but most of the people there did not know that I have SCD or how seriously it has affected my life. Speaking in front of my community wasn't easy, but it also felt very powerful to share my testimony in this way. After our presentation, we held a blood donor registration session and 74 people pledged to be a blood donor.

At first, I wasn't sure how I would be useful in the team because of my health, however, after our training, and a few meetings and events, my experience has been that... I love what I do with South London Gives! I am also aware from the feedback I get from my manager, fellow volunteers and our



Some of the South London Gives Team

- Sharing their personal experiences of receiving life-saving blood transfusions, being a first time blood donor, and having a family member with sickle cell.

In our second year, South London Gives will continue to contribute to the numbers of people from black and mixed race communities

signing up to the blood donation register. NHSBT estimate that 40,000 new donors from these groups are required to meet the needs of sickle cell patients across the UK.

Want to get involved?

Like giving blood, getting involved is simple and easy, you can:

- Sign up to the blood donation register here: bit.ly/SouthLondonGives
- Become a Community Advocate bit.ly/SLGcommunityadvocate
- Invite us to your London based workplace, church or group. Contact: Tracy Williams, Project Manager, tracy.williams@sicklecellsociety.org

communities that my perspective as someone reliant on blood transfusions is a really important part of the project. I would encourage anyone thinking about volunteering with SLG to get in touch. We are waiting to welcome you!

Carlton
business owner, first time blood donor

Giving blood had crossed my mind several times over the years. Being from a mixed race background I was aware that blood from black and mixed race people is needed for people with sickle cell disease. I don't have any personal connection to sickle cell myself and don't know anyone with it.

About ten years ago, I went to a hospital that had a 'Give Blood' sign outside and asked if



I could donate that day. They sent me away and said I could only do it somewhere local to me. To be honest, I was really deflated after that, it put me off and giving blood fell off my radar for a bit. I didn't have the inclination or the time to look into trying again until I was approached by one of the South London Gives team a few months ago.

When I went for my appointment, I was treated really respectfully and the atmosphere was friendly and welcoming. They were able to draw my blood in 4 minutes, which I understand is really fast for a first time donor! I have already booked for my next donation. After giving blood I felt pleased that I had done something positive to help others. After a week or so I got a letter telling me which hospital my blood had gone to which really added to the sense of satisfaction I had about going ahead and donating for the first time. I wish I had done it sooner.

FUNDRAISING SPOTLIGHT



A massive thank you to **Jemima** (aged 11) for raising £577.57 through her 1000 Bounces for Sickle Cell Fundraiser.



A big thank you to **Steven Birch** for raising £425 by running both the **Worthing Half Marathon** and **Southampton Marathon**



A huge thank you to **Jones and Walker Productions, Yaxley FC, Hunts FA, the Sons of Marcus Garvey and the Sons of Outta Town** for their charity football match. Together they raised £1210!



A big thank you to **Ruarn Rankin** who took on a seven mile, 40+ obstacle mud run to raise £565.56 to support our work

A massive thank you to **Anne Isaacs** for her 10,000ft tandem skydive which raised £3040 for **Lupus UK, IOSH Benevolent Fund** and us

A big thank you to **Diane Hasan Kocacinar** who raised £880 in memory of her mother who passed away

Thank you to all of our **Facebook Fundraisers** for raising money for us, with a special thank you to **Kilali Ominu-Erbota, Jackie M Jay and Andrea Bedward** who were our top fundraisers



A huge thank you to **SELCO Wembley** who donated £250 worth of games, electronics and other products



A massive thank you to **Mariette Clarkson** who raised £1550 through a sponsored hair cut



A big thank you to **Theresa Logun** who cycled 300 miles from **Brussels to Frankfurt** and raised £1013.89 to support our work



A massive congratulations and thank you to **Anthony King and Michelle Barned** who completed the **Thames Bridges Trek** and raised over £2000!



A big thank you and congratulations to **Nicole** for running the **Sheffield 10k** to raise money and awareness for sickle cell



A huge thank you to dedicated fundraiser, Naomi White, who has done it again, this time swimming the Catalina Channel and raising £1,390. Last year she raised money swimming the English Channel



A massive thank you to Michele Quest, Jessie Ofei and everyone involved in the KPMG Fundraising and Awareness Event held at their Canary Wharf Office



A huge thank you to the team at Sainsbury's and Argos for raising £310 through their Black History Month Fundraisers



A massive thank you to Daniel Owens for raising £730 through his Nightrider Cycles fundraiser



A big thank you to the British Nigerian Law Forum for raising £1160 at their Gala and Dinner Awards



A huge thank you to Trevor and everyone at SLR for donating £310.25



A massive thank you to the Royal Mail for their Black History Month Exhibition and fundraiser in support of our work!



A huge thank you to Doye Balogun for running the Royal Parks Marathon to raise money to support our work



ODD SQUAD

Another massive thank you to the Odd Squad (Steph, Sheree, Emma, Sarah, Angie, Sam, Mina, Minaxi, Angela G, Sandra, Arlene, Tony, Peter, and Sati) for their continued fundraising efforts

They have engaged in a whole range of fundraising efforts as part of our 40th Anniversary celebrations including bake sales and fitness boot camps. Most recently the Odd Squad ran the Royal Parks half marathon with support from Cllr Luke Patterson from Brent Council who joined the team for the run

The Odd Squad have been inspirational in demonstrating the power of working together to raise money and awareness for sickle cell. So far they have raised a massive £10,678

I Am Number 17

One in 17 people in the UK will be affected by a rare disease*. The I Am Number 17 campaign visually depicts the experiences of 17 people living with rare diseases.

I Am Number 17 is a campaign to help the voices of those with rare diseases be heard, brought to you by Takeda, together with 13 rare disease patient groups from across the UK.

At the forefront of the campaign are 17 'changemakers', people living with a rare disease or supporting someone who has a rare disease. The changemakers share their personal experiences through works of art created with paired artists from around the country.

The goal is to increase understanding of what it's like to live with a rare disease – and show that rare isn't always that rare.



The Exhibition

On Wednesday 22nd January, the I Am Number 17 campaign was officially launched with a gallery opening evening at the OXO Tower gallery. The invited guests included the project artists, changemakers, patient groups and

other people involved with rare diseases. The evening saw talks from the managing director of Takeda UK, Jon Neal; changemakers David and Lara; Dr Richard Scott from Genomics England; Takeda Europe and Canada President, Giles Platford; and Baroness Blackwood gave a speech via video.

The rest of the evening was spent enjoying the 17 pieces of art created as a collaboration between changemakers and artists. One of the pieces on display was a piece of artwork called *A Captive of Crisis* which was created by Rachel Sawyer to share our lead mentor, June

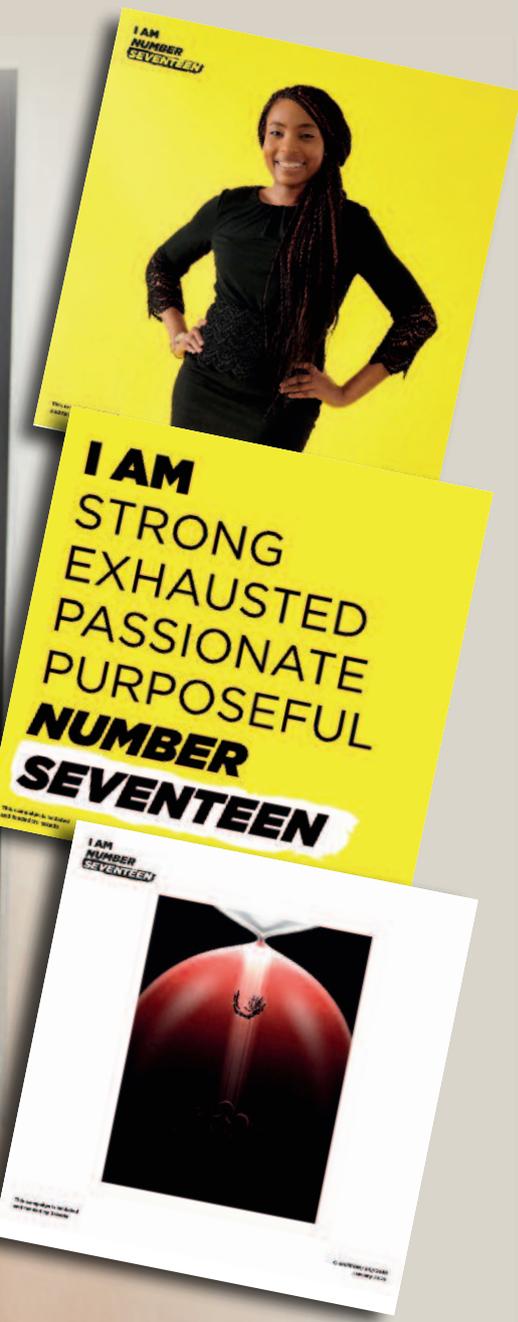


Okochi's experience of living with sickle cell.

"I was diagnosed with sickle cell, a genetic blood disorder that affects the red blood cells. My loved ones are an essential part of me getting through this disease. I am one of the 17." June Okochi

Read more about our lead mentor June, her involvement in the campaign, the artwork created by Rachel Sawyer and the I Am Number 17 campaign at: www.iamnumber17.geneticalliance.org.uk

*www.raredisease.org.uk/what-is-a-rare-disease/. Accessed January 2020
This campaign is initiated and funded by Takeda.



SCDAA Conference

On October 9th, SCS Chief Executive, John James OBE, attended the Sickle Cell Disease Association of America's (SCDAA) 47th Annual National Convention in Baltimore. The theme for this year's four-day conference was

Sickle Cell Community Embracing Change

Together and was designed to address the multi-factorial aspects of sickle cell and trait.

John gave a presentation in his capacity as Co-Chair of a Global group of Patient Advocacy Groups and Clinicians entitled *Strategies Used for Management of Sickle Cell Disease and Evaluation of Patient Satisfaction Levels: An Interim Analysis of the International Sickle Cell World Assessment Survey [SWAY]*. He also attended talks and had a chance to network with other sickle cell organisations.



John James OBE with Lanre from the Sickle Cell Awareness Group of Canada and with Cassandra Trimmell, leader of Sickle Cell 101 in the USA



John James OBE with Karina Ngaiza (front left) and the USA ASH (American Society of Hematology) team

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

You can contact our helpline service on **020 8963 7794** between: 10am and 5pm Monday – Wednesday

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

We are also on social media: [@SickleCellUK on Facebook, Twitter and Instagram](https://www.facebook.com/SickleCellUK)

Alternatively, please write to us: Helpline Services Team, **Sickle Cell Society, 54 Station Road, London NW10 4UA.**



The Sickle Cell Society is Britain's only national charity for sickle cell disorders, an inherited haemoglobin disorder. The Sickle Cell Society was founded in 1979 by a group of patients, parents and health professionals who shared concerns about the lack of understanding of sickle cell disorders and the inadequacies of treatment. We aim to raise awareness of sickle cell disorders, push for

improvements to treatment and provide advice, information and support to the sickle cell community. We produce information resources about sickle cell disorders, and hold at least three education seminars a year, as well as other awareness events. We provide a helpline service as well as an annual children's holiday to provide a respite break for children with sickle cell disorders and their families. We undertake lobbying work to draw attention to issues affecting the sickle cell community.

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



Sickle Cell Society patrons, Kym Mazelle and Baroness Dame Floella Benjamin at our 40th Anniversary Gala Ball

www.sicklecellsociety.org/donate