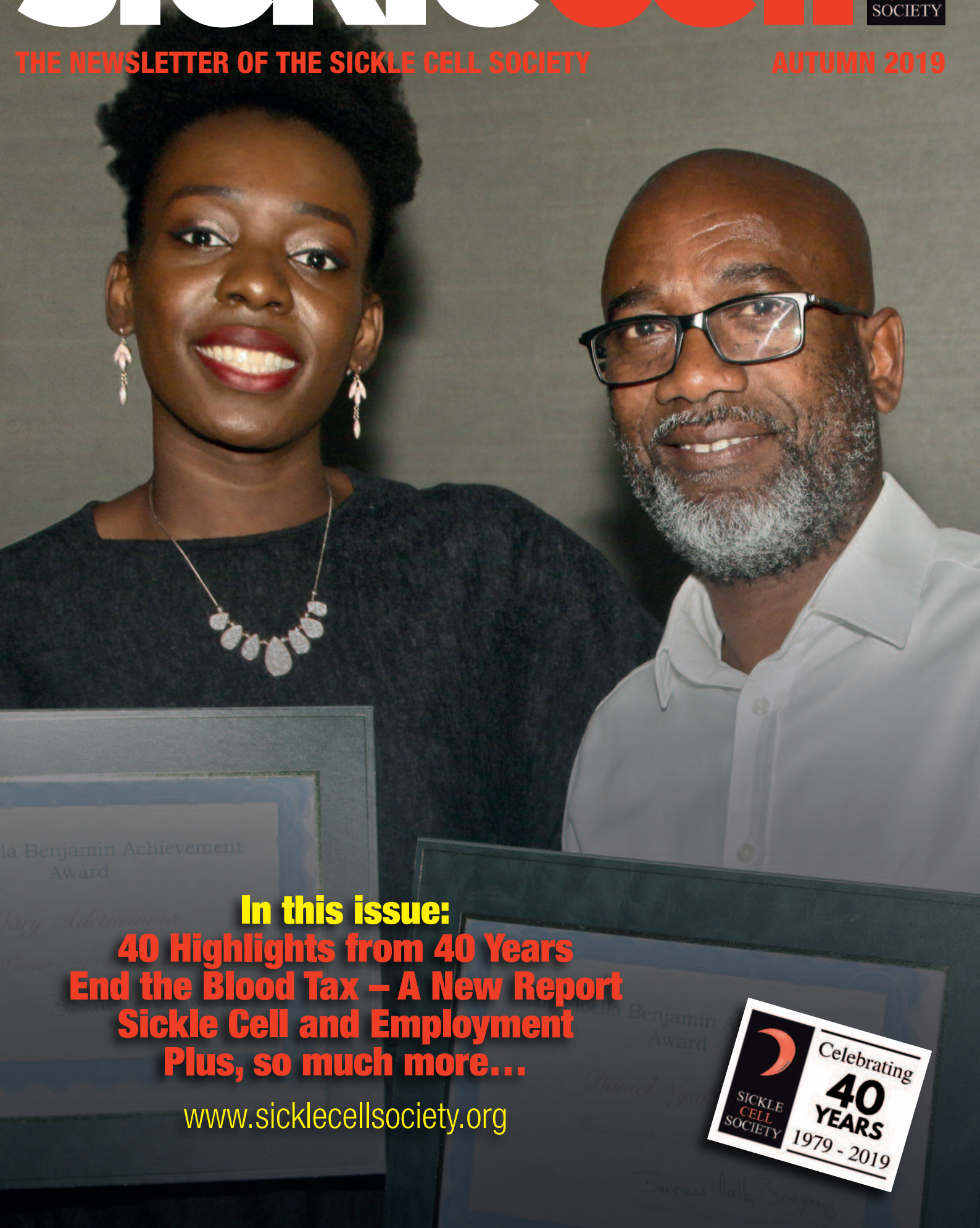


sicklecell



THE NEWSLETTER OF THE SICKLE CELL SOCIETY

AUTUMN 2019



In this issue:

40 Highlights from 40 Years
End the Blood Tax – A New Report
Sickle Cell and Employment
Plus, so much more...

www.sicklecellsociety.org



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Cover: Mary Adeturinmo and Daniel Nyakutsey with their awards at our 2019 AGM

Introduction

As you are probably aware, 2019 marks the 40th Anniversary of the Sickle Cell Society. We want to say a huge thank you to everyone who has supported us over these 40 years. The last six months has been business as usual but we have also been busy organising celebrations and events to mark this important milestone. For 40 years we have been working hard alongside the sickle cell community to champion progress and support those most in need. Looking back over the work that has been done since 1979, it is great to see the progress that has been made. There is still lots of work to be done and we hope that the next 40 years will be even more impactful.

We are celebrating this important anniversary with a range of events and celebrations. For example, in March we headed to Stoke-on-Trent to partner with SCIPE at their annual Heart and Soul Uplifting concert. This musical concert saw performances from the B-Positive Choir, the Emmanu'-el Apostolic Gospel Academy, Donna Marie, Peter Spence and DD King. As well as spectacular performances, the concert raised awareness and funds to support our work. A special thanks to our trustee, Carol Burt, and everyone at SCIPE for organising this fantastic event. Thank you to everyone who came along and who donated.

Later in March the Odd Squad team (including our trustee Sheree Hall) took to raising money through a Fitness Boot Camp. This fundraising event raised over £600 and was all about having fun, getting fit, and celebrating 40 years of the Sickle Cell Society. A huge thank you to everyone who came and to our trustee Sheree, and everyone else who was involved in organising it. They have more fundraisers planned so keep an eye on our social media for more details.

As part of our celebration for World Sickle Cell Day (alongside our *Did You Know* awareness campaign) we teamed up with the South Yorkshire

Sickle Cell Organisation to run the Sheffield Patient Education Day. Opened by the Lord mayor of Sheffield, the day saw talks from NHS staff, clinicians, nurses and others on a range of topics including clinical trials, the NHS England Sickle Cell Service Review and paediatric care.

Then on the 23rd June, we took to the beautiful St Marks Church in Kennington for our 40th Anniversary Thanksgiving and Celebration Service. This annual event is a chance to look back and celebrate the lives of those we have lost, the achievements made so far and the whole sickle cell community. We were delighted to have our patron, Rev. Rose Hudson-Wilkin give the address, as well as having Rev Canon Stephen Coulson, the Mayor of Lambeth Cllr Ibrahim Dogus, Classical Reflection, and service users and medical professionals in attendance.

We would like to say a big thank you to all our donors, fundraisers and supporters this year whose support is vital for our work to continue. A special thank you to Stanley Marrast, Shirley Burry, Marcel Dubell, and Daniel North who took on 110km in the Isle of Wight Challenge, raising almost £4,000. You can read more about our other fundraisers on page 18.

We are looking forward to our Fundraising Gala Ball in September. Hosted in the Royal National Hotel, the Gala Ball will be a glamorous evening of music, dance, food and more. With special celebrity guests



and performers, a delicious hot three-course buffet, an excellent DJ and a chance to win unique prizes at the Fundraising Raffle and Auction. It will be a fantastic celebration of 40 years.

As well as celebrating, we have also been marking our anniversary with research and parliamentary work. In July, as our role as secretariat of the Sickle Cell and Thalassaemia All-Party Parliamentary Group we published *End the Blood Tax – An Investigation into the Impact of Prescription Charges for those Living with Sickle Cell and Thalassaemia*. The report aims to quantify the anecdotal reports we hear time and time again from service users and health professionals. Prescription Charges have always been an issue which we have been passionate about, as shown by our work with the Prescription Charges Coalition. More on this latest report on page 13.

Other research we have been involved with is 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 have recruited 200 patients to take part in this global project and are looking forward to seeing the results and sharing them with you.

We are excited that in our 40th year we have been named one of Mayor of Brent, Cllr Ernest Ezeajughi's charities of the year. The Sickle Cell Society has a long history in the borough of Brent with our main offices located in Harlesden and being set up in Brent in 1979. We are

delighted to have been chosen as one of Mayor Ezeajughi's charities. We are grateful to the Mayor for this exciting opportunity and look forward to working alongside him throughout the year.

In other exciting news we are also delighted to announce that the Sickle Cell Society have been selected as a Global's Make Some Noise charity! Global's Make Some Noise funds and empowers charities like us, helping disadvantaged children, young people and their families across the UK. We are excited to be working alongside them to raise awareness of sickle cell.

We also started early discussions with Kings Health Partners about the possibility of creating the UK's first institute for sickle cell disorder. This is still at an early development phase but we hope it comes to fruition and helps shape high quality improvements in sickle cell care for patients and families for the next 40 years.

As we celebrate 40 years of working within the sickle cell community we also look forward to continuing this work for the next 40 years and continuing to see progress being made. We hope you enjoy reading about our history in this newsletter and that you will become part of our future as we continue to strive to improve the care for people living with sickle cell across the UK.

John James OBE CHIEF EXECUTIVE and

Kye Gbangbola CHAIR OF TRUSTEES

Sheffield Patient Education Day

On the 21st June 2019 the Sickle Cell Society joined the South Yorkshire Sickle Cell Organisation (SYSCO) to host the Sheffield Patient Education Day.

Celebrating both the Society's 40th Anniversary and World Sickle Cell Day (which was two days before) the Sheffield Patient Education Day was a chance for parents, children, carers and health professionals to come together to learn more about sickle cell.

The event was opened by the Lord Mayor of Sheffield who said a few encouraging words followed by John James OBE who thanked people for coming. The first talk was by Dr Josh Wright who gave a fascinating presentation on the upcoming clinical trials for sickle cell in the UK and explained the different stages trials go through and the new ways they are looking to treat sickle cell.

Mark Thaxter from NHS England then gave an update on specialised commissioning and the haemoglobinopathy service review (Sickle Cell Service Review). He explained in more detail about the procurement of Haemoglobinopathy Coordinating Centres and took questions from the audience. Dr Josh Wright then spoke again, this time



expanding on Mark's talk and how it will affect South Yorkshire.

Shaun Emmitt then gave a presentation on paediatric services in Sheffield and explained the transition process for young people. Finally, Gloria Ogunbadejo spoke about the Sickle Cell Society's National Helpline and the wider social support which is available to people living with sickle cell and their families.

Hannah and Navlet Reid concluded the day by sharing the story of the South Yorkshire Sickle Cell Organisation and provided information about how people can get involved.

To find out more about the South Yorkshire Sickle Cell Organisation visit their Facebook Page:

<https://www.facebook.com/syccosheffield>

40th Anniversary Thanksgiving Service

The Sickle Cell Society Celebrates 40 Years with Thanksgiving Service

To mark 40 years of serving the sickle cell community, the Sickle Cell Society held a Thanksgiving and Celebration Service at St Marks Church, Kennington.

On Sunday 23rd June, the Sickle Cell Society held a Thanksgiving and Celebration Service at the beautiful St Marks Church in Kennington. The theme for this years' service was '40 Years of Caring' and was a time to reflect on the progress made so far, remember those who have passed away and look forward to the future.

Rev Canon Stephen Coulson gave the

welcome and this was followed by readings, prayers and traditional hymns. Readings and prayers were given by sickle cell supporters, service users, carers and health care professionals.

The address was delivered by Rev. Rose Hudson-Wilkin, Chaplain to the Speaker of the House of Commons and was an inspirational Christian message with a bit of good humour thrown in. Rev Hudson Wilkin also pledged her support by offering to be a blood donor for our South London Gives Project which was there to encourage attendees to sign up as blood donors.

There were also talks from Cllr Ibrahim Dogus, Mayor of Lambeth, John James OBE (Chief Executive SCS) and Michele Salter (Vice-Chair SCS).

To set the celebratory tone the service also included musical performances from soloist Savannah Hall and Classic Brit Award nominees, Classical Reflection.

The Thanksgiving and Celebration Service was also an opportunity to raise funds to support the work of the Sickle Cell Society. Over £575 was raised which will go to improving sickle cell care at a local and national level.



Savannah Hall giving a beautiful performance



Rev Rose Hudson-Wilkin, Rev Canon Stephen Coulson, Mayor of Lambeth Cllr Ibrahim Dogus and John James OBE



Society members and supporters enjoying the Thanksgiving Service



Otis Roberts (Jason Roberts Foundation), Mayor of Brent Cllr Ernest Ezeajugh, Kye Gbangbola (SCS Chair), and Dawn Butler MP at the Mayor Making Ceremony

Mayor of Brent's Charity of the Year

On Wednesday 1st May, newly elected Brent Mayor, Cllr Ernest Ezeajugh, announced his two charities of the year at the council's Mayor Making Ceremony.

Cllr Ezeajugh became the First Citizen of Brent last Wednesday 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 will be supporting throughout his year in office: the Sickle Cell Society and the Jason Roberts Foundation.

The Sickle Cell Society has a long history in the borough of Brent with their main offices located in Harlesden. First set up as a

registered charity in Brent 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 locally and across the country.

Sickle cell is a cause close to the new Mayor and Council's heart, as the late Brent Councillor, Tayo Oladapo, lived with sickle cell before sadly passing away in 2016. Early this year, with the support of current and ex-councillors, the Society raised funds for a headstone to mark Tayo's grave.

Being chosen as one of the Mayor's charities provides an opportunity to raise awareness of sickle cell, the work the Society does and to

raise funds to support the continuation of the support the Society offers. The Mayor has already started the fundraising at the Brent Council Windrush Afternoon Gala Celebration on 22nd June.

"We are delighted to have been chosen as one of Mayor Ezeajugh's charities, particularly as we are celebrating our 40th Anniversary. Although we are a national charity, our roots are in Brent and supporting people living with sickle cell in Brent has always been important to us. We are grateful to the Mayor for this exciting opportunity and look forward to working alongside him throughout the year."

John James OBE

World Sickle Cell Day

On the 19th June we celebrated World Sickle Cell Day. The 19th June was officially chosen as a day to raise awareness for sickle cell in 2008 by the United Nations. We celebrated with a dedicated web page to help raise awareness. We also created information packs which we

sent out to members and on social media to help everyone promote awareness and we shared our 'Did You Know Campaign'.



Social media was buzzing with different people sharing articles and information. We shared articles from the Huffington Post, BBC News, NHSBT and more.

World Sickle Cell Day also saw the launch of the trailer for 'Untold Sickle Cell Stories' a Global Photo Essay by Novartis featuring lead Sickle Cell Society mentor, June Okochi. You

can find out more about that at:

<http://untoldsicklecellstories.com>

Two days after World Sickle Cell Day we also held a patient education day in Sheffield. You can read more about this elsewhere in the newsletter.



Formation of the Sickle Cell Society



First London to Brighton Bike Ride was held in memory of Geoff Johnson whose daughter had SCD



Launch of the Annual Children's Holiday



2017



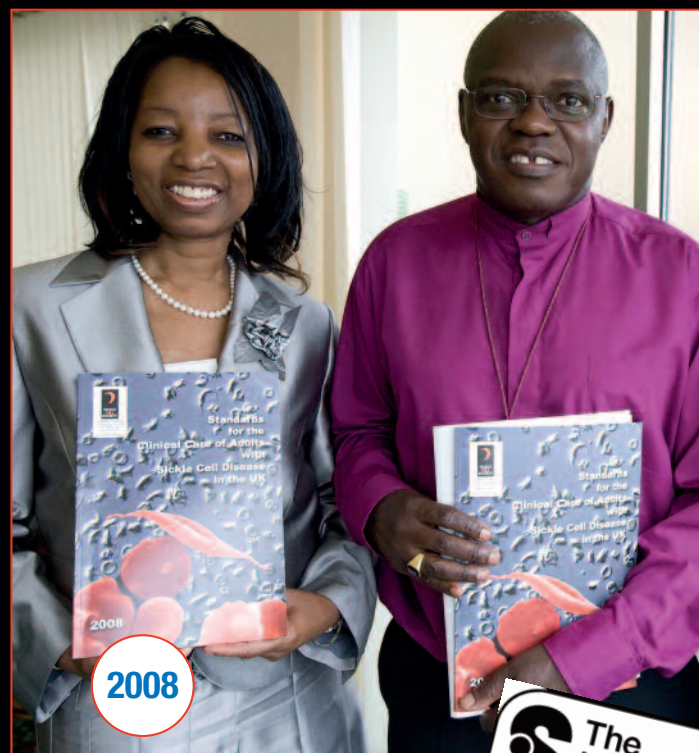
Hackney and City Mentors Whitney, Michael, and June

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Sickle Cell Society Top 40 Highlights from 40 Years



Sickle Cell Society presents four Graseby Infusion Pumps to North Middlesex Hospital



Dr Lorna Bennett and Archbishop Dr John Sentamu at the House of Commons Launch of the Adult Standards of Care for People with SCD



Baroness Cumberlege from the Department of Health speaking at the Sickle Cell and Thalassaemia National Conference



- 1 Formation of Sickle Cell Society 1979
- 2 Sickle Cell Society donates £1,800 to Central Middlesex Hospital to purchase Screening Equipment 1981
- 3 Sickle Cell Society donates £5,000 to Willesden Hospital to purchase a computer 1982
- 4 First London to Brighton Bike Ride was held in memory of Geoff Johnson whose daughter had sickle cell disorder 1984
- 5 Presented two 'on-demand' analgesia computer pumps to Central Middlesex Hospital 1985
- 6 A conference on Sickle Cell Chaired by Lord Pitt 1986
- 7 Launch of the Annual Children's Holiday. The first holiday saw 20 children living with sickle cell and 7 nurses travel to Bognor Regis. 1988
- 8 The Sickle Cell Society and the Sickle Cell Anaemia Research Foundation (SCAR) jointly fund research grants 1989
- 9 Sickle Cell Society presents four Graseby Infusion Pumps to North Middlesex Hospital 1991
- 10 First Sickle Cell and Thalassaemia National Conference took place at Aston University, Birmingham 1993
- 11 The Ralma Faulkner Welfare Fund and Bryan Jones Education Fund established 1996
- 12 National Health Service Sickle Cell and Thalassaemia Screening Programme (NHSSCTSP) was set up. Sickle Cell Society was part of the lobby for a Screening Programme 2001
- 13 Production of audio tape Understanding Sickle Cell Disease a Guide for Parents of Newly Diagnosed Children by Dr Nelly Adjaye, Dr Kofi Anie, Lorna Bennett, and Barbara Brewster and a host of expert patients 2002
- 14 Launch of the Regional Care Advisor Programme funded by the Community Fund and Big Lottery Fund in five regions of the England 2004
- 15 Launch of the National Sickle Cell Helpline 2004
- 16 33rd Summit of UNESCO Paris declares Sickle Cell Disease a Global Public Health Priority supported by representations from the Sickle Cell Society's Dr Asa'ah Nkohkwo 2005
- 17 A Wellcome Trust funded doctor-patients engagement workshop on managing sickle cell pain is held at the Society supported by the UK Forum on Haemoglobin Disorders 2005
- 18 Sickle Cell Society hosted at 10 Downing Street by Cherie Blair 2006
- 19 Launch of Sickle Cell Society Educational Scholarship with support from Novartis 2006

- 20 Launch of the *Standards for the Clinical Care of Children with Sickle Cell Disorders in the UK* **2006**
- 21 Full roll out of the Newborn Screening **2006**
- 22 Sickle Cell Society partner with Imperial College for the first prototype Sickle Cell Anaemia Detector (SCAD) camera for the in vivo investigation of the sickling process **2007**
- 23 Sickle Cell Society Celebrates first World Sickle Cell Day (Adopted by the United Nations General Assembly) **2008**
- 24 Dr Norman Parker publishes the first ever National Confidential Enquiry into Patients Outcomes and Deaths involving Sickle Cell patients and the Sickle Cell Society active on the NCEPOD Expert Panel **2008**
- 25 RH Norman Lamb MP and Archbishop Dr John Sentamu hosts the House of Commons Launch of the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK* **2008**
- 26 Launch of the All-Party Parliamentary Group **2008**
- 27 Sickle Cell Society achieves NHS Information Standard, led by trustee Kye Gbangbola **2012**
- 28 The UK's largest sickle cell patient survey conducted with CLAHRC North West London, National Institute for Health Research, Roald Dahl's Marvellous Children's Charity and the Picker Institute Europe. **2015**
- 29 The Spectra Optia Apheresis System cleared by the National Institute for Health and Care Excellence (NICE) – Automated Red Cell Exchange said to save the NHS nearly £13 million a year **2016**
- 30 Launch of the Hackney and City Mentoring Programme **2017**
- 31 Updated Pain Management Guidance for NHS Emergency Departments (NICE) **2017**
- 32 Sickle Cell Society participates in the NHS Sickle Cell Service Review **2018**
- 33 RH Diane Abbott MP hosts the Parliamentary Launch of the 2nd edition of the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK*, Editorial Group Chaired by Dr Jo Howard **2018**
- 34 Sickle Cell Society wins the GSK IMPACT Award - a national award that recognises charities that are doing excellent work to improve people's health and wellbeing **2018**
- 35 Sickle Cell Society is accredited against the Investors in People standard –the international standard for people management **2018**
- 36 The Sickle Cell and Thalassaemia All-Party Parliamentary Group publishes '*How Did You Contract That*' a report into the institutional failures of Personal Independence Payment (PIP) and '*I'm In Crisis*' a report into the lack of representation that sickle cell disease and thalassaemia has in pre-registration nurse and midwife education. **2018**
- 37 Provider arrangement with NHS BT for the launch of the South London Gives project **2019**
- 38 Brent Mayor, Ernest Ezeajughi, selects Sickle Cell Society as one of his Charities of the Year **2019**
- 39 Launch of the Self Over Sickle Podcast; the UK's first podcast on sickle cell **2019**
- 40 Secured agreement with NHS England and the Haemoglobinopathies Clinical Reference Group to consider the introduction of a policy for Haematopoietic Stem Cell Transplant for adults with sickle cell **2019**



Chair of Trustees, Kye Gbangbola with Mayor Ernest Ezeajughi at Mayor Making Ceremony





South London Gives at City Hall - Aliya Gladyn, Sadiq Khan, Michele Salter, Tracy Williams, and Iyamide Thomas



Pastor Agu Irukwu RCCG, Pastor Yemisi Ashimolowo KICC, Cherie Blair, Dr Bennett Sickle Cell Society, Pastor Dipo Oluoyomi KICC at Downing Street



Chief Executive John James OBE and trustees Kye Gbangbola, Michele Salter and Carol Burt at the GSK Impact Award ceremony



Dr Jo Howard speaking at the launch of the Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK



The SCTAPPG outside Parliament with the 'I'm In Crisis' report

AGM 2019

<https://www.sicklecellsociety.org/employment/>

The celebrations continued with the raffle and award ceremony. We had two awards this year; the Floella Benjamin Award and the Black on Black Award.



Floella Benjamin Award

The Floella Benjamin Award was established by Baroness Floella Benjamin OBE in the 1990s. The certificate is presented to individuals or groups who have realised a significant achievement for sickle cell i.e. by fundraising, or a personal achievement by a person(s) with sickle cell disorder.

Winner:

Mary Adeturinmo

Runners up:

Nora Molongwe and
Daniel Nyakutsey

Black on Black Award

Established thanks to our patron, Trevor Philips OBE, during his days as editor at the London Weekend Television in the 1990s. The certificate recognises creative work by a person personally suffering from sickle cell.

Joint Winner:

Deborah Thomas and
Nora Molongwe

On Saturday 20th July we held the Society's 40th Annual General Meeting at De Vere Grand Connaught Rooms in Central London. The AGM is a chance to review the previous year, celebrate 40 years of supporting the sickle cell community and learn more during the educational sessions.

The official part of the AGM began with an introduction by Chair of Trustees, Kye Gbangbola. This was followed by a look through the audited accounts and annual report by Vice-Chair and Treasurer, Michele Salter. The final part of the official section was an open Q and A for members to voice their questions and concerns.

After a delicious lunch and chance to network, the day continued with education sessions. The first of these sessions was by the Infected Blood Inquiry team (Rochelle Powel,

Paralegal and Brian Stanton, Director) and Mike Stredder, Director NHSBT. They gave a talk on their work. For more information on the Inquiry please read our Spring 2019 newsletter which features an article by Rochelle Powell.

The second session was on Clinical Trials by Willem Scheele MD (Chief Medical Officer, Imara Inc.) and Dr Rachel Kesse-Adu (Consultant Haematologist, Guy's and St Thomas NHS Foundation Trust). They presented the most recent research which Imara was doing as well as explaining the process of clinical trials through each stage.

Finally, Professor Simon Dyson (De Montfort University, Leicester) presented the collaborative work he has been doing on Sickle Cell and Employment. You can read more about this elsewhere in the newsletter. You can also download the most recent guide here:



Professor Simon Dyson presents the Guide to Sickle Cell and Employment



Mary Adeturinmo and Daniel Nyakutsey with their awards



Rachel Kesse-Adu shares her expertise on Clinical Trials



Nora Molongwe and Deborah Thomas receive their awards presented by John James OBE



Willlem Scheele MD presents on Clinical Trials



Mike Stredder and Brian Stanton presenting on the Infected Blood Inquiry

40th Anniversary Appeal

For 40 years, the Sickle Cell Society has been delivering research and educational projects, supporting individuals and families and influencing policy.

As well as celebrating the achievements of the Society, we need your help to ensure we can continue to make a positive difference to people affected by Sickle Cell Disorder over the next 40 years.

Your support is invaluable to us. We're asking you to fundraise, donate, take part in, or run your own event, volunteer or help us raise awareness. Every bit of help from you will make a difference.

Please help us to achieve £40,000 and make our 40th Anniversary appeal a success!

Set up your own fundraiser or donate here:

<http://bit.ly/SCS40>



A huge thank you to everyone at the Sickle Cell Society AGM 2019 for comments on the guide to sickle cell work and employment! Please visit the website for updates on the project:

<http://sicklecellwork.dmu.ac.uk> Read on to find out more about what we did with the advice given to us by members at the Sickle Cell Society AGM:

We asked you to decide between two front covers. Thanks to Sandra Oliver, an expert in sickle cell and dyslexia from the West Midlands, who advised us on the need to make the guide accessible for those with dyslexia, and suggested we have the final version printed on cream paper rather than white. This advice also influenced the audience on the day, who voted 46-34 in favour of the cover chosen. As many of you wanted a combination of the two covers, we acted on a suggestion of Dame Elizabeth Anionwu and created just one letter in red. Other good suggestions were also acted upon: we have noted on the front cover that the guide is for both **employers** and **employees** and we have included the project web-site on the front cover so that it is more prominent.

Next we asked if you liked the idea of a **Worker's Individual Support Plan** (building on the idea of a Statement of Special Educational Needs or and Individual Education Health and care Plan used to support children with medical conditions in schools). We felt that **Worker's Individual Support Plan** might help communicate the seriousness of the issue and could be referred back to at a later date. It seems that this was a very popular proposal with 78 people agreeing that a **Worker's Individual Support Plan was a good idea**, and only eight being unsure (this is how we interpreted the eight of you who ticked both *Yes* and *No* in answer to this question!). No-one thought this was a bad idea, and so this has been retained as an integral part of the policy guide.

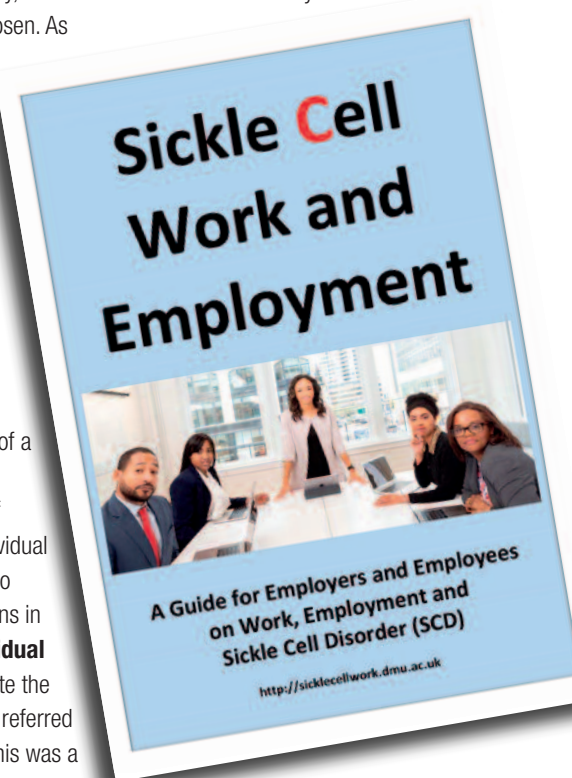
We then asked if you thought anything was missing. There were some very important suggestions made, and here are some of our thoughts in response.

A few mentioned the need for information on schools and there is already a Guide to Sickle

Sickle Cell Work and Employment

By **Simon Dyson** and **Maria Berghs**,
De Montfort University

Cell and School Policy and this can be downloaded from the web-site: <http://sicklecellanaemia.org/school-policy-guides/> or obtained from the authors or through the Sickle Cell Society.



Others mentioned the need for guidance for university students with sickle cell disorders (SCD). We do have some information on this from our interviews with 47 adults living with SCD and we will try to work with this information to put some information up onto the project web-site.

A couple of respondents at the AGM noted that our guidance does not address those who are *self-employed*. We recognize that there is an issue of the difficulty of switching between self-employment when well, and the need for support and perhaps benefits when not well, and we will look further at this. Meanwhile

there is some advice on social security benefits up on the project web-site (<http://sicklecellwork.dmu.ac.uk>) and we thank Daniel Nyakutsey of the South East London Sickle Cell Centre at Wooden Spoon House for sharing his expertise on completing applications for personal independence payments.

For those who wanted more medical details, we do have a further document, developed by a young graduate of De Montfort University, Dorcas Oyeyiola, who has produced an A-Z of Sickle Cell Symptoms and Reasonable Adjustments that employers might make to support a worker with SCD. This is available on the project web-site under the tab *Reasonable Adjustments*.

One issue beyond the scope of the current project, but of enormous importance, is the challenge that parents, especially mothers, face in trying to keep paid employment when having to take time off work to care for a child with SCD who is poorly. We are aware of several who have lost jobs in this way and this is an important issue requiring further research and documentation of the challenges facing parents in such circumstances.

Finally, many of you kindly gave us suggestions and contact details for organizations that we might contact to try to influence policy. We hope to take up as many of these as possible and to be able to visit local support groups to share the research finding and make available hard copies of the guide for your use. Thank you again to the sickle cell community for your invaluable support, to the 47 interviewees living with SCD who kindly gave us hours of their time, and to Vanetta Morrison and Kalpna Sohkal who drafted the guide together with ourselves.

We would like to thank all of the partners involved with the project: Big Lottery Fund, DRILL (Disability Research Independent Living and Learning), De Montfort University, OSCAR Sandwell, and the Sickle Cell Society.

Finally thank you to Iyamide Thomas of the Sickle Cell Society and Rachel McFee of OSCAR Sandwell who have been instrumental in making the project a success. We hope the guide makes an important difference to experiences of employees with SCD in the future.



End the Blood Tax

All-Party Parliamentary Group for Sickle Cell and Thalassaemia releases new report into the impact of prescription charges for those living with sickle cell and thalassaemia.

'End the Blood Tax' is the latest report from the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG) in collaboration with the Sickle Cell Society, which investigates the impact prescription charges are having on people living with those conditions.

There are countless anecdotal reports from qualified nurses, doctors, other allied health care professionals and most significantly service users about the effect of prescription charges on the day-to-day lives of service users. This had provided an insight into the struggle and human cost that endless prescription charges present to those living with sickle cell disorder and thalassaemia. The SCTAPPG set out to research this area in the hope of shedding light on what is an effective tax on blood, and a tax on sickle cell disorder and thalassaemia. It will offer an insight into the real life experiences of those living with sickle cell disorder and thalassaemia and how prescription charges impact their daily lives.

The report was launched at the Extraordinary General Meeting (EGM) of the SCTAPPG held in Portcullis House on the 26th June. The objective of the research is to enable service users to have a voice in this debate and provide a condition specific analysis of how prescription charges affect their day-to-day lives. It is hoped that this report can serve to add the mounting

body of evidence, which is as clear as it is vital, to exempt those with long term conditions from these charges.

The meeting also included the election of a new chair; Rt Hon Pat McFadden MP (Wolverhampton South East) and a new Vice Chair: Janet Daby MP (Lewisham East). Together they discussed the report with other attendees including service users, health professionals and MPs: Ian Austin MP (Dudley North), Preet Kaur Gill MP (Birmingham, Edgbaston), Liz Kendall MP (Leicester West), Peter Kyle MP (Hove) and Eleanor Smith MP (Wolverhampton South West).

Key Findings:

70.1% of respondents informed us that they had used either savings, an overdraft facility or a payday loan to be able to afford their prescription.

This illustrates that the current situation is not sustainable, all three of these solutions have drawbacks. The use of savings acts as a penalty and fosters financial insecurity. Pay day loans possess extra exorbitant charges which only serve to rise indebtedness. It should not be the case that anyone shouldn't be able to meet their most basic health needs, however currently this is how the system exist

88% of respondents asserted that they either always or sometimes had difficulty with their

prescription payment.

This exists for both those who purchase the prescription prepayment certificate and pay the £9 charge and illustrates that the system systematically causes stress and difficulty to those with sickle cell and thalassaemia.

Over half of the cohort (52%) revealed that they had infrequently or sparingly taken their medicine due to the cost.

This is in direct contradiction of doctors' orders who have clear advice on the most effective amounts of medicine. This illustrates the impact of burgeoning prescription costs and how people are being forced to choose between their health and their economic security. Moreover, people not being sufficiently medicated leads to strain on primary care services, therefore making this an economic as well as moral tragedy.

SCTAPPG Recommendations

The SCTAPPG would echo the Prescription Charges Coalition's recommendation and petition the Department of Health and Social Care (DHSC) to immediately grant exemption to sickle cell disorder and thalassaemia along with all other long-term health conditions.

Conclusion

The data suggests that the current system is not fit for purpose, our members are effectively being taxed for the blood they have and were born with. We are calling for an end to the blood tax.

To find out more about the report, other key findings recommendations and to read it in full download it at:

www.sicklecellsociety.org/endthebloodtax/



Self Over Sickle

What a busy and exciting time it's been with the Self Over Sickle Project!

Since the launch of the project in 2018, which saw a number of workshops rolled out across South London and Birmingham, to the reformation of the project to offer the UK'S first podcast on sickle cell, the project has gone from strength to strength to engage more young adults across England and beyond. Sharing the first-hand stories and experiences of people living with sickle cell as well as their advice to power through (and that of health and industry professionals), the episodes equip listeners with the know-how, empathy and motivation needed to press forward.

After tuning into an episode for the first time, one listener described the podcast as 'inspirational' saying they 'cried tears of joy'



Stefan and Jenica Leah recording in the Pod at White City Place

because "sickle cell is a thing that no one understands unless you have it".

Another said they loved the idea of hearing those with sickle "talk candidly about their life and experiences" whilst another listener from Ireland said "none of my friends and family go through this illness [so] it's great listening to people I know go through it too".

Stefan, a 23-year old living with sickle cell SS and presenter on The Self Over Sickle Podcast shared his enjoyable experience on the

show saying, "it's provided me with the satisfaction of being able [to] make such an impact in the community. The project started halfway through my third year [at university] and carrying on as I embark on my career. I've been really motivated through this period as I see how much my peers with sickle cell have and are achieving. I looked forward to leaving lectures and recording the podcast because it was so much fun and I was even more educated on my condition."

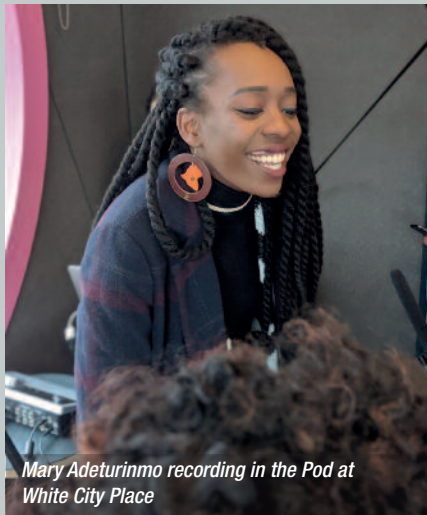
A Very Public Goodbye



Topics that have been explored in the GOALS series include, Relationship Goals, Career Goals, Life Goals and Squad Goals with episodes being specially recorded in The Pod at White City Place and live episodes taking place at Merton ArtsSpace.

To celebrate the launch of what has been an empowering movement for sickle cell warriors everywhere, the Self Over Sickle Launch party was held in Croydon at Project B where all had the opportunity to learn, grow and share with each other. Featuring a panel of special guests including Chanel Taylor (UnsickleMyCells), Kehinde Salami (Sicklekan), Emmanuel Botchway (MyFitability) and Alidor 'A Star' Gaspar, hosted by Self Over Sickle's very own Mary Adetunmo, the night was full of laughs and networking complete with tasty refreshments, the beautiful voice of Gold and the sounds of MyselfMyles. One highlight of the night was that everyone aforementioned had sickle cell demonstrating to many that although you may have sickle cell, sickle cell does not have to have you; in limiting dreams or achievement.

After a thriving 600 plays on the podcast and in aid of Sickle Cell Awareness Month, warriors UK-wide also had the opportunity throughout July to share their experiences on the topics from the podcast series and interact with each other via our Instagram Story Takeover. Hosting the Self Over Sickle Instagram story for the day, warriors and advocates shared stories, answered questions and were reminded they are not alone.



Mary Adetunmo recording in the Pod at White City Place

The final event in the series concluded with the topic My Goals, in which warriors and carers met together to explore activities around

communication, aspirations and ultimately the vision for one's life.

Participants were inspired by the words and experiences of each other and left empowered to live the life they wanted, complete with their own visionboard made in the session.

The Society would like to thank all the sickle cell warriors that worked with the Patient Education & Training Lead on this project, extending a special thank you to Stefan Taylor, Jenica Leah and Mary Adetunmo who worked tirelessly and remarkably on every episode.

To see what you've missed and get involved with what's coming, visit the Sickle Cell Society YouTube page and follow us on Instagram @selfoversickle.



Emmanuel Botchway, Kehinde Salami, Jenica Leah, A Star, Mary Adetunmo and Angel Cake sharing about her new YouTube channel at the SOS Launch Party



On 29 May 2019, Public Health England staff and others associated with the NHS Sickle Cell & Thalassaemia Screening Programme (NHSSCTSP) bid goodbye to Cathy Copping, the NHSSCTSP Programme Manager as she retired after an NHS career spanning over 40 years! It has been a pleasure working collaboratively with Cathy and the Sickle Cell Society wishes her a well deserved retirement. Cathy is standing centre back!

Sickle Cell in the News



Noel Phillips

On Saturday 27th July news reporter, Noel Phillips, published an article on the Sky News website about sickle cell patients being denied benefits. The article looked at warnings coming from MPs, including chair of the Sickle Cell and Thalassaemia All-party Parliamentary Group, Pat McFadden.

The article coincides with the findings of our report, *How Did You Contract That?*, a report into the institutional failures of Personal Independence Payment (PIP) for those living with sickle cell disease and thalassaemia.

The article also contains a video interview with Anita Enanejewa a mother of someone living with sickle cell.

You can find a link to the full article here: <https://www.sicklecellsociety.org/skynews/>

South London Gives

Increasing blood donation in people of black African and black Caribbean heritage

For the past 6 months the Sickle Cell Society has been running a new project supported by NHS Blood and Transplant (NHSBT) aimed at increasing blood donation in people of black African and black Caribbean heritage.

The project primarily focuses on four south London boroughs: Greenwich, Lambeth, Lewisham and Southwark, with the aim of encouraging black and mixed heritage people to talk about blood donation, breaking down some of the myths, preconceptions and fears that exist around the topic and encouraging people to sign up to become regular blood donors in their communities. We were thrilled that during her address at our Thanksgiving Service in June, the new Bishop of Dover and Sickle Cell Society patron, Rose Hudson-Wilkin pledged her support to the project and signed up as a donor.

In 2015 NHSBT commissioned a research report which detailed some of the barriers that prevent different ethnic groups from donating blood. In black African and black Caribbean communities this included a lack of awareness of the need for more black and mixed heritage

donors; unfounded fears that donating blood can harm ones' health, and a reluctance to engage with the donation process due to negative experiences of the NHS and other statutory organisations. **In addition, many black or mixed heritage donors are not aware that you can still donate blood if you have the sickle cell trait.** South London Gives addresses some of the recommendations in the report by training Community Advocate volunteers about the blood donation process and how they can talk to people about the concerns and fears that stop some individuals and communities registering to donate. The volunteers then share their knowledge with their family, faith and professional networks and

sign up people to the blood donation register. South London Gives also attends colleges, educational establishments, churches, community festivals and large work places to provide information about blood donation and register people, regardless of their ethnicity, as potential donors.

You can get involved with South London Gives by:

- Volunteering as a Community Advocate
- Inviting us to talk to your group about blood donation
- Registering to give blood: bit.ly/SLGiveBlood

Read the ESRO report about BAME Blood Donation: bit.ly/ESROreport

For more information about the project or to invite us to talk to your group, please contact:

Tracy Williams

Project Manager, Community Organising:
tracy.williams@sicklecellsociety.org
T. 07809 736099



Sickle Cell and Blood Donation on BBC Radio 4

On Tuesday 30th July at 11am, BBC Radio 4 aired a documentary titled *The Black Blood Crisis* by Lindsay Johns (Produced by Giles Edwards) which explored the shortage of BAME blood donors and why blood donation is so important. The show explored the difference between reasons and excuses for not

donating, how we can overcome those barriers and why blood donation is such an important topic. We also heard an interview with South London Gives volunteer, Dunstan, who shared his experience of living with sickle cell.

You can listen to the programme on the BBC Sounds website.

Hackney and City Mentoring Programme

As most of you will know, the Sickle Cell Peer Mentoring Programme has been successful in terms of its engagement with children young people and parents, clinicians, commissioners, including the demand and uptake not just from City and Hackney but from most boroughs across London.

We were also fortunate to have had the opportunity for the programme to be published in the British Journal of Haematology in Spring of 2019 outlining the outcomes of the model on children and young people. Our mentors were at the British Society of Haematology Conference in Glasgow in April 2019 to present their work.

We are pleased to announce that the Sickle Cell Society are currently in early conversations with all of the East London Clinical Commissioning

Groups (CCGs) across the 7 boroughs about the potential expansion of the City and Hackney Sickle Cell Peer Mentoring Programme which has successfully piloted over the last 2 years.

Whilst these conversations are taking place, we intend to pause referrals into the programme to manage demand and capacity. The break will commence from 30th June 2019. This means the mentors will take a short break from mentoring young people to ensure that the wider expansion to all of East London is successful. We hope the programme will resume hopefully in the winter or early next year, 2020 and will be re-launched. We will keep you informed of the progress of the programme expansion.

If you have any queries, please do not hesitate to contact the Sickle Cell Society on info@sicklecellsociety.org

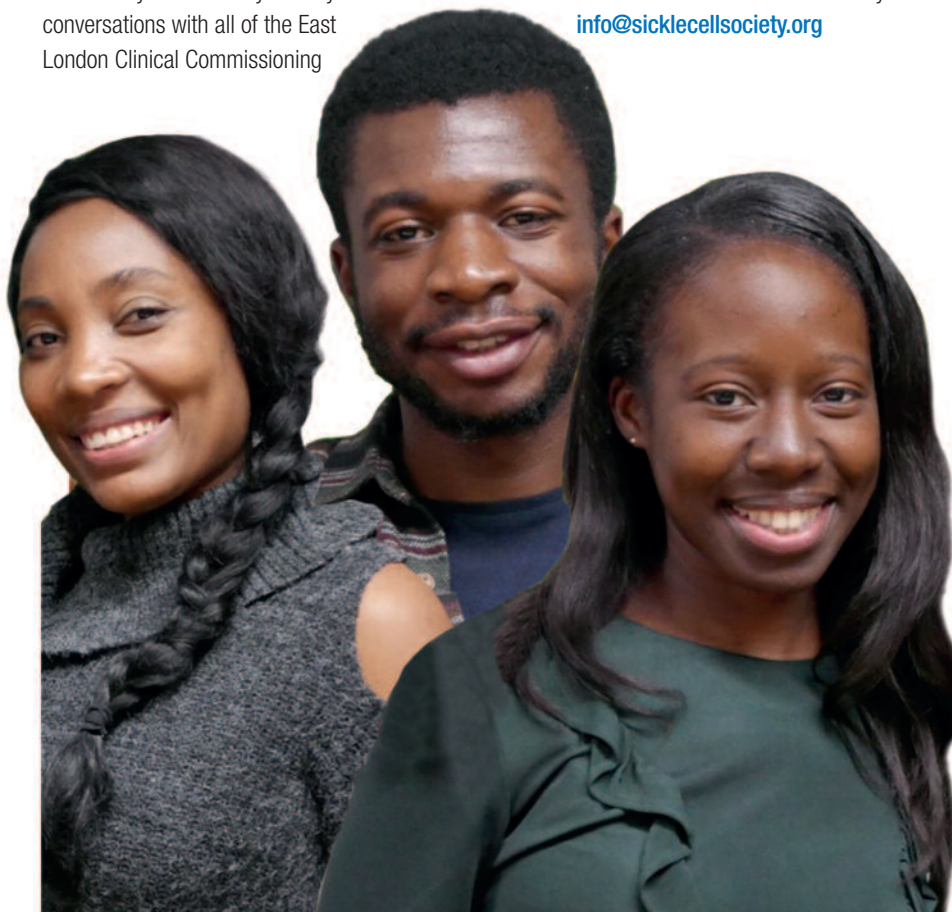


Headstone Fund for the late Cllr Tayo Oladapo – An Update

It's three years now since we had the shock of the late Councillor Tayo Oladapo's untimely death aged 34. Thanks to wonderful supporters we have been able to raise funds for a headstone to mark his grave in the Paddington Old Cemetery for family and friends to remember his life and his contributions to London Borough of Brent and beyond.

Tayo was remembered during the prayers of a mass at the Sacred Heart of Jesus in Kilburn on the 30th March. This was followed by a memorial held at his graveside.

Tayo was an excellent example of someone holding public office whilst living with sickle cell disorder. We are grateful to everyone who contributed to the fundraiser and we hope that the headstone will mark his grave for his family and other loved ones as well as to remember Tayo and to help inspire other people living with sickle cell disorder to be aspirational.



FUNDRAISING SPOTLIGHT



A massive thank you to the Odd Squad (Steph, Sheree, Emma, Sarah, Angie, Sam, Mina, Minaxi, Tony, Peter and Sati) for their many 40th Anniversary Fundraisers. As a team they have raised over £6000 through a Fitness Boot Camp, bake sale, garden tea party and more. They are also running a half marathon in October. You can support them here: www.justgiving.com/fundraising/oddsquad



A massive thank you to Nicolle Akinnewu and everyone at YPOM for running the Big Half and raising over £1200!

A big thank you to Barbados & Friends Association who raised £475 for us.

A massive thank you to MANSAG (Medical Association of Nigerians Across Great Britain) for raising £500 to support us.

Thank you to AFC Lewisham, Phillemon and Josephine for raising £106 through their football tournament.

A huge thank you to Westcliff High School for Girls and Boys for raising money for us at their fantastic event.

A big thank you to Pastor Chuka Nwafor for a super successful fundraising jazz

A huge thank you to Daniel Owens who is doing four cycle rides of 100km each through London, Liverpool, Glasgow and Bristol this year.

Thank you to all of our Facebook Fundraisers for raising mioney for us, with a special thank you to Toyin Adeotoye, Robert White, and Jummyk Olad who all raised over £500 each.



A big thank you to the Onyemara Nwanneya Women's Association for raising money to support our work



A huge thank you to Yvonne Harewood and everyone at the Barbados Day in Reading. They raised £475 to support our work. Thank you to the Mayor of Reading, Barbados and Friends Association, Trevor Small and the High Commissioner for Barbados



A huge thank you to Satinder Reehal who raised £500 from a cake bake at her Gurdwara Temple on Saturday 4th May!



A huge thank you to Yvonne Knight for organising a fantastic fundraising ball in February

40 Portraits of Pain

By June Okochi



A huge thank you to everyone who ran the Hackney Half Marathon for us!



A massive thank you to Stanley Marrast, Shirley Burry, Marcel Dubell, and Daniel North who took on 110km in the Isle of Wight Challenge! Plus, they have raised almost £4,000!



A huge thank you to Nicole for raising money to support our work by running the Run Heaton Half Marathon!

I love telling stories. I write about my experiences of life, art, travel, culture, poetry. I even journal about living with my genetic condition.

But one day I decided it would be great to express in a different kind way. I wanted to tell mine and other's stories of living with our genetic condition through visual imagery.

I wanted to use photography as an art form to express the different emotions that come with this condition.

How we deal with pain and suffering every day of our lives. To express how we battle fatigue levels, how we live with anxiety about when next we will be sick and back on a hospital bed, how we have become accustomed to discomfort and pain that we are no longer afraid of it. We have normalised it like the air we breathe. How we deal with broken bones, broken cells, strokes, suffocating pain, damaged organs and fight early mortality. Sometimes the pain is so excruciatingly unbearable, we chose death over life.

We are born with it and we die with it. There are no easy ways around it.

We deal with the impact on our social lives, our physical, mental and emotional lives. It takes its toll on our childhood, education, careers, professions, everything, until we end up borderline depressed and broken but we keep going, we keep living, we smile, we hide behind our pain, we cry at night, we keep smiling, we keep thriving, we keep popping those pills, we pop them until we die, we take your blood and exchange them into our veins to have life, to live. We need your blood donations, it fixes us for a short time until the next time

when we need another fix. We take opiates to keep us alive, pain free. We use oxygen to keep us alive, we use surgery and chemo treatments to keep us alive. We do everything we can because we have no choice, because we didn't choose this, because we were made to deal with it.

Some of us do not know what a decent quality of life looks like.

We fight, we fight, we win, we lose. Some fall and don't make it, we hold their memories, recognising that they are in a better place, pain free, others keep fighting until we make our



mark, find our legacy and our legacy may be as simple as just surviving.

Sickle Cell...

I am a warrior. We are warriors.

Watch out for the full online photography series exhibition coming soon.

Creator: June Okochi

Photographer: Jim Higham

Creative Director: Ijeoma Okochi-Agwu

Production: Mica Marshall and Tommy Okochi

Global's Make Some Noise

We're delighted to announce that the Sickle Cell Society have been selected as a Global's Make Some Noise charity!

Global's Make Some Noise funds and empowers small charities like us, helping disadvantaged children, young people and their families across the UK.

Global's Make Some Noise is supported by the media and entertainment group, Global, home to some of the UK's biggest radio brands including Heart, Capital, Classic FM, Smooth,

LBC, Radio X, Capital XTRA and Gold. They come together to raise money and awareness for small charities like us, and provide training to boost skills and build sustainability.

On Friday 11th October we'll be taking part in Global's Make Some Noise Day. All of Global's radio brands and people up and down the country will be doing something to shout about, big and small, to raise money for Make Some Noise.

Find out more here:

www.makesomenoise.com



Update on our Screening Programme Engagement Project

By **Iyamide Thomas**, NHS Engagement Lead, Sickle Cell Society

Let's Recap

In this our special 40th Anniversary newsletter we have had a forty year 'recap' on things the Society has done in reaching this tremendous milestone. However, rest assured this is not



Iyamide Thomas

another 40 year recap (!) but one that will take you back only a year to August 2018 when the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) were commissioned by the NHS Sickle Cell and Thalassaemia Screening Programme ('Screening Programme') to work collaboratively with them

to understand the reasons for variation in performance by screening providers and find ways to improve performance. This is the 'Engagement Project' I shall update you on.

In July 2018, the Screening Programme defined the year's key work priorities. These were for SCS and UKTS:

To review and update (in collaboration with relevant health professionals) the 'Sickle cell disease in childhood: standards and guidelines for clinical care' publication which was last updated in October 2010.

To support the actions and recommendations from the 'Parents' Stories' publication we produced in a previous tender, which documented people's personal experiences of the Screening Programme.

To Support the Screening Programme in its Newborn Outcomes System (NOS) which is an automated system that supports the referral of babies diagnosed with sickle cell into treatment.

What have we achieved in Year 1 (August 2018 – August 2019)?

'Sickle cell disease in childhood: standards and guidelines for clinical care'

A Standards Working Group (SWG) was formed whose main aim was to oversee the various drafts of the document and ensure the accuracy of its content. This group had Dr Moira Dick (Retired Paediatrician and Sickle Cell Society Medical Advisor) and Professor David Rees (Professor of Paediatric Sickle Cell Disease, King's College Hospital) as Clinical Leads and included other clinicians, specialist nurses and reps from SCS and UKTS. At its first meeting the SWG decided it was more appropriate to call the document 'Sickle cell disease in childhood: standards and recommendations for clinical care' rather than

'guidelines'. A Medical Writer / Editor with expertise on sickle cell was recruited to proof, edit and comment on the various drafts, cross-check references and produce a well laid out document ready for publication. The draft document (and an executive summary) was sent out for three week online consultations to health professionals and other relevant stakeholders including service users. A focus group with parents of children with sickle cell was also held to get more comprehensive feedback on the document, which will firstly be published online (end of August 2019) before it is produced in hard copy and officially launched.

The 'Sickle cell disease in childhood: standards and recommendations for clinical care' (3rd Edition) publication has been written to support paediatricians, haematologists, specialist nurses and psychologists, and those responsible for monitoring outcomes i.e. hospital trusts, commissioning authorities and peer-review services. Our aim is to ensure that every child has access to the same quality of care wherever they live in the UK.

'A Parent's Guide to Managing Sickle Cell Disease'

During our Project Advisory Group discussions on updating the 'Paediatric Standards' we decided that we should also update the 2012 edition of 'A Parents' Guide to Managing Sickle Cell Disease' (a book which parents are given especially when they have just had a child with sickle cell disease) and include in a 2019 edition any additional wider determinants of health relevant to living with sickle cell which service users ask for. As such, I am part of an editorial team with Dr Lola Oni, Service Director of Brent Sickle Cell & Thalassaemia Centre and other health

Iyamide (in yellow) with a cross section of parents and two children at the focus group consultation in July



professionals to update the publication. We have designed a questionnaire which will be used to consult parents on which information they have found useful in the old edition and what additional things they might want included in the new.

'Parents' Stories'

The 'Parents Stories' raised a number of screening issues for the public (present early in pregnancy, contact maternity and specialist counselling centres direct as well as your GP), for screening providers (provide direct access to Specialist Nurse Counsellors to known 'at-risk' couples), and community groups (raise awareness in your communities about the importance of early screening). The SCS / UKTS have raised awareness of these issues through their various networks including at road-shows, TV interviews (e.g Hellenic TV – Greek and Omega Live TV - Ghanaian) websites, newspaper and newsletter articles, patient education days and talks at health professional forums and service user support groups.

Newborn Outcomes System (NOS)

The NOS is an automated system that supports the referral of babies diagnosed with sickle cell into treatment and also links to the National Haemoglobinopathy Register (NHR), a confidential database of patients with mainly sickle cell disease and thalassaemia major living in the UK. Through their various networks as described earlier the SCS / UKTS have been raising awareness of the NOS and NHR helping to improve families understanding and trust for use of their data. Patients have been encouraged to register on the NHR and see it as a way of subsequently improving commissioning and targeting of resources since it will help identify patient numbers in certain areas. The UKTS has led on drafting new user-friendly patient information leaflets and posters on the NHR and are piloting these with service user focus groups. SCS has been raising awareness of the importance of penicillin and immunisation and the need for newly diagnosed sickle cell babies to be seen by a clinician within 90 days, especially among new parent support groups.

What is planned for Year 2?

The NHS Sickle Cell and Thalassaemia Screening Programme are in the process of confirming the various aspects of their work



Team UKTS' with nurses from Birmingham City Hospital after a UKTS Patient Education Day

they will want the two Societies to help with and mainly bring the user perspective to. We will be publishing the updated version of 'A Parents' Guide to Managing Sickle Cell Disease' in Year 2. The SCS / UKTS will also

help the Screening Programme with the updating of their counselling competences last published in 2013. The Societies and service users they recruit will be part of the working group and will review and comment on the revised competences. Some new work around reporting of sickle cell carrier status is also envisaged. We will continue raising awareness of the NOS and NHR especially after the new posters and leaflets are piloted.

As Year 1 of the project ends we have once again successfully demonstrated the benefits of collaborative working between the Screening Programme (providers of a service) and the Sickle Cell and UK Thalassaemia Societies (which represent users of the service) and how this can lead to ways of service improvement.

Bianca Elgar – Sickle Cell Partnership



The Sickle Cell Society is excited to be partnering with Bianca Elgar. Bianca Elgar is the multi-award-winning, Founder and Artistic Director of the Bianca Elgar design brand. She first approached us back in 2018 with a desire to help us raise awareness and funds to support our work.

This year she has chosen to donate 10% from the online sales of selected items in her Home range to us as part of our 40th Anniversary celebrations in 2019. The new collection of lifestyle accessories features the beautiful Men and Women prints found in the Out of Africa collection, inspired by Bianca's travels around Northern Africa.

The beautiful collection includes silk scarfs, posters, t-shirts, note cards, mugs, throws and wrapping paper. All of these items can be bought here: <http://bit.ly/biancaelgarcollection>

Bianca was recently featured in Goldie Magazine, the print magazine for flourishing-over-40, talking about her designs: "I was fascinated by the many representations of masks, shields and beads. To me, these symbolise both protection and defence and it made me think about how we wear a variety of masks throughout our lives and also how a mask can offer a safe space to develop yourself and try out new things" Bianca Elgar, Goldie



Magazine April 2019

We look forward to working with Bianca throughout our 40th Anniversary celebrations. You can find out more by reading her blog post here: <http://bit.ly/SCSbiancaelgar>

Three years ago the Sickle Cell Society received funding from the Big Lottery fund to launch the Sickle Cell South London Link project.

Since the project came into fruition it has made a big impact demonstrating the need for services within the Sickle Cell Community.

Since its launch it has held over 50 activities for children and young people including days out such as bowling, trampolining, go-karting, DJ-ing masterclasses, cooking classes, theatre trips and so much more. As well as activities we have also provided workshops covering themes and topics such as reducing stress and anxiety, managing pain, managing school & friendships and communicating with their Doctors and Consultants at appointments. The children who have participated have fed back the positive impact these days out have provided such as peer 2 peer support, reducing isolation, increasing confidence and feeling more positive about living with SCD.

In addition, for parents/carers and adults living with SCD we have held workshops on pain management, benefits, education & care plans, managing school & friendships, healthy eating, managing stress, anxiety & depression, transitioning into adult services (for young people). This too has demonstrated an increase in confidence, reduced isolation, peer 2 peers support and enhancing knowledge to manage areas such as employment, returning to employment and so on.

Alongside this, throughout the lifespan of the project, we have recruited 40+ volunteers, many living with SCD or carrying the Sickle Cell Trait. Volunteers have been busy giving up their time to support our

project activities and the work of the Society, in areas such as outreach work, helping with administration and office duties, providing peer 2 peer support at support groups, helping at children's activities, the list has been endless! Volunteers have also received first aid training & training on looking after someone who lives with SCD.

On top of this we have worked closely with support groups to build capabilities across Lambeth, Lewisham and Southwark as well as other areas such as Croydon, Wandsworth and Merton. And even wider such as Essex! Topics have included areas such as increasing governance, members, advertising working in collaboration with other organisations, raising awareness of SCD. This has led to fruitful outcomes such as support groups networking and building relationships and gaining further knowledge on how to set up a support group or take an existing support group forward.

It has been a pleasure leading the project for the last 3 years and seeing first-hand the impact the project has had for individuals living with SCD both younger and older and parents & carers. The project has demonstrated the need for such services and while it is sad to see the project come to an end in August 2019, it has been fantastic seeing the positive impact it has made.

Thank you to all those who have participated including the volunteers for giving up their time. Valerie and I have enjoyed working with you all.

Donna Prendergast
South London Community Manager

South London Link



Making A Difference – A Journey with NIHR CLAHRC NWL event

On Thursday 6th June, Trustees, Kye Gbangbola and Ganesh Sathyamoorthy, Chief Executive John James OBE, and Self Over Sickle project leader Siann Millanaise, attended the CLAHRC NWL Making a Difference event. The event celebrated 10 years of CLAHRC NWL (National Institute for Health Research: Collaborations for Leadership in Applied Health Research and Care (Northwest London)).



The Sickle Cell World Assessment Survey (SWAY)

The Sickle Cell Society has been working in partnership with Adelphi, Novartis and other sickle cell organisations across the world to recruit for the Sickle Cell World Assessment Survey (SWAY). SWAY is a global survey of sickle cell patients and treating healthcare professionals aimed at understanding the current burden of disease and unmet needs in sickle cell patients.

SWAY will cover the following topics:

- 1 Impact of sickle cell on patients in terms of symptom, emotional and financial burden and the impact on daily living
- 2 Current management approaches for sickle cell, treatment goals and the level of satisfaction
- 3 Level of patient engagement and knowledge about sickle cell
- 4 Interaction between patients and the healthcare system
- 5 Availability of resources to support sickle cell management

The Society has managed to get 200 participants and are looking forward to seeing the results from across the world.



John James OBE at a global meeting of sickle cell organisations in London in March discussing SWAY. With him are Beverley Francis-Gibson, President and CEO of the Sickle Cell Disease Association of America and Lanre Tunji-Ajayi, CEO of the Sickle Cell Awareness Group of Ontario.

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

T. 020 8963 7794

between: 10am and 5pm Monday – Friday

You can also use our confidential email service:

helpline@sicklecellsociety.org. We are also on social media: [@SickleCellUK on Facebook](#), [Twitter](#) and [Instagram](#).

Alternatively, please write to us:

**Helpline Services Team, Sickle Cell Society,
54 Station Road, London NW10 4UA.**



Sickle Cell Anaemia Capital Radio Helpline - Thursday 31st May 1984



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
T: 02089617795

If you are no longer receiving letters or emails from the Society but would like to, please email info@sicklecellsociety.org to say that you wish to opt-in to Sickle Cell Society communications. We will then update our database. You can contact us at any time to opt-out

www.sicklecellsociety.org