

sicklecell



THE NEWSLETTER OF THE SICKLE CELL SOCIETY

AUTUMN 2018



In this issue:

Highlights from the 2018 AGM

The Emmanuel Amuta Poetry Award – winning poems

Launch of the new Sickle Cell Standards

Plus, so much more...

www.sicklecellsociety.org

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New Privacy Policy

We are sure that you got hundreds of GDPR emails and letters a few months ago, so we are very grateful to everyone who responded to ours. We promise to never share your data without your permission and have recently updated our privacy policy to be completely GDPR compliant. You can view the new privacy policy here: www.sicklecellsociety.org/privacy-policy/



We value your data and will never share it without your permission. We are so dedicated to protecting your data that we got assessed positively against the Cyber Essentials Scheme Test Specification as shown by this certification badge.

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.

MESSAGE FROM JOHN JAMES AND KYE GBANGBOLA

Over the last six months the Society has had lots to celebrate. We launched a new set of national standards for the care of adult sickle cell patients across the UK, we were one of eight winners of the prestigious GSK Impact Awards, we were awarded Investors in People accreditation, we hosted our 39th AGM and so much more. We hope you enjoy reading about all the progress that has been made and join with us in looking forward to our 40th year.

We were very excited to launch the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK* in May at the Houses of Parliament. The Standards are a collaborative resource with input from healthcare professionals and patients. It had been 10 years since the previous standards were published, so a 2nd edition was long overdue. We know that informed patients are better able to participate in their healthcare decisions, so we want to see the standards become a tool to enable this. We hope that the standards will be taken up by patients, healthcare professionals and many others as an invaluable resource to improve the care that sickle cell patients receive.

Later in May, we were very privileged to attend the 2018 GSK Impact Awards, together with other Society board members; Michele Salter (Vice Chair/Treasurer) and Carol Burt (Trustee) as well as our partners from City and Hackney Clinical Commissioning Group; Charlotte Painter (Programme Director for Long Term Conditions, NHS City and Hackney CCG) and Cathy Coppinger (Programme Manager, NHS Sickle Cell and Thalassaemia Screening Programme, Public Health England). This is a significant achievement and we are very proud to have been a winner.

On 19th June we celebrated World Sickle Cell Day, a day chosen by the United Nations to raise awareness of sickle cell. We celebrated by joining others in education and awareness campaigns, writing a blog

for the NHS website and also by hosting a Facebook Live to discuss the new plans by NHS England for sickle cell services. It was great to see so many people raising awareness and coming together to support the sickle cell community.

The Sickle Cell Service Review has been one of our main focuses over the last six months. Commissioned by NHS England, working with the Clinical Reference Group for Haemoglobinopathies and the Sickle Cell Society, the review looks at haemoglobinopathy services, particularly how short and long stay admissions to hospital is provided. It has been an ongoing process and we have been working hard on making sure every person with sickle cell has their say. Through a survey, events, a

Facebook Live (which has received almost 2000 views and almost 200 comments) and at our AGM, we have been collecting your thoughts to feedback to NHS England. Together this is a powerful message to the NHS for proper consultation around sickle cell services. You can read more about it later on in the newsletter.

I was also very excited to have received an OBE in the Queen's Birthday Honours in June. This honour reflects the significant progress being made by the Society. I was delighted to share the good news with my family, friends and colleagues and hope that it will help raise the profile of the important work we do as a charity.

Despite many challenges, the last six months

have been full of celebrations and we are very grateful to all the hard work of our staff, volunteers, trustees, patrons, supporters, partners, donors and all the support groups up and down the country. As we look forward we are excited to be going into our 40th year and all that brings. Keep an eye out for our 40th Anniversary celebrations and how you can get involved. We know that as the weather gets colder and the sky gets darker, the sickle cell community will continue to support each other and that together we will continue to have lots to celebrate.

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



John James OBE

Kye Gbangbola

Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK



Picking up a copy of the new Sickle Cell Standards

The Sickle Cell Society launched a new set of national standards for sickle cell at a reception hosted by the Rt Hon Diane Abbott MP.

On Wednesday 2nd May the Sickle Cell Society in partnership with the UK Forum on Haemoglobin Disorders launched the 2nd edition of the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK*. The Standards were launched at a reception in the Attlee Suite, Portcullis House, hosted by the Rt Hon Diane Abbott MP, Chair of the Sickle Cell

and Thalassaemia All-Party Parliamentary Group (SCTAPPG). The launch was attended by parliamentarians, healthcare professionals, patients, service users, and other groups and individuals dedicated to seeing services for sickle cell disease improve. The Standards have been updated from an earlier edition released ten years ago and aim to continue improving care for sickle cell patients and reduce inequalities across the country.

The launch reception was opened by the Rt Hon Diane Abbott MP (Chair of the SCTAPPG)

and saw talks from patients on the impact of sickle cell disease on their lives. Consultant Dr Jo Howard (Chair of UK Forum on Haemoglobin Disorders and Chair of the Editorial/Writing Group for the development of the new adult Standards) outlined the significance of these new standards and the improvements the Standards aim to make for patients. There was also a talk from Kye Gbangbola (Chair of the Sickle Cell Society) and John James OBE (Chief Executive of the Sickle Cell Society).

The publishing of these new standards has been a collaborative effort which consulted leading sickle cell healthcare professionals and sickle cell patients in order to document the minimum standard of care patients should be receiving and outline ways in which these standard can be achieved.

In 2008, the Sickle Cell Society, working with leading sickle cell experts and sickle cell patients, published the first edition of the Standards. The Standards were a significant step towards improving sickle cell services and in the ten years since they were published care for sickle cell patients has improved but there is still a long way to go. The new Standards will build upon the progress made by the first edition and aims to ensure that sickle cell patients across the country receive the same

high level of care.

As well as launching the new Standards, the reception served as an opportunity for individuals and groups to network and combine efforts to see the continued improvement of care.

The new Standards can be downloaded at the Sickle Cell Society website: www.sicklecellsociety.org/sicklecellstandards/ For more information please contact **Matthew Neal** at matthew.neal@sicklecellsociety.org



Dr Jo Howard

The Rt Hon Diane Abbott MP, Chair of the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG), said:

"I am pleased to endorse the new Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK. These new standards play a significant role in improving the care of adults living with sickle cell in the UK. There is still a disparity in the quality of care across the different regions of the UK but these standards are a great step towards ensuring that every sickle cell patient, whatever region they live in, get the same high quality of care."



Rt Hon Diane Abbott MP

Dr Jo Howard, on behalf of the Editorial/Writing group and the UK Forum on Haemoglobin Disorders said:

"The second edition of the 'Standards for Clinical Care of Adults with Sickle Cell Disease in the UK' (2018) is an important document aiming to improve care and reduce inequalities for adults with sickle cell disease. It outlines minimum standards of care across the UK and has retained key standards from the first edition (2008) and has updated or added new standards where needed. This represents a significant piece of work and was led by the Sickle Cell Society in collaboration with members of the UK Forum on Haemoglobin Disorders and the wider UK haemoglobinopathy community. We hope all those involved with the care of those with sickle cell disease in the UK will utilise it for patient benefit and to improve outcomes."

John James OBE, Chief Executive of the Sickle Cell Society said:

"We are very proud to be releasing the 2nd edition of the Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK. We hope that the Standards will become an invaluable tool for all key stakeholders of the condition to use to ensure that they are meeting best practise. The previous Standards played an instrumental role in improving care for sickle cell patients but there is still much to do. The 2nd edition of the Standards will be another significant step towards improving care across the country."



John James OBE



Whitney Joseph providing a patient perspective

Breaking Down Barriers

Breaking Down Barriers is a project focused on helping people living with sickle cell to overcome the various barriers they face. This could be anything from language barriers stopping them accessing informational resources to not being able to get the work or education that they want. Our Breaking Down Barriers project officer, Linda, has been very busy for the last few months; from attending awareness events to creating informational leaflets. Read on to find out about all the things she has been involved with.

Informational Leaflets

Brand new educational leaflets "Did You Know?" for ages 5-10 and 11-16 have now been created for people who speak French and Portuguese. The leaflets were developed in response to finding that the languages spoken by the largest amount of people with sickle cell in the UK (after English) was French and Portuguese. The leaflets aim to empower the

French and Portuguese speaking communities to become more informed about sickle cell.

These informational leaflets (in English, French and Portuguese) have now been spread far and wide and most recently to the Marcus Lipton Community Enterprise in Lambeth. Working with community and youth centres, places of worship and other community spaces is an important part of spreading awareness.

Employment

On Wednesday 11th April 2018, Linda attended De Montfort University in Leicester to take part in the project 'Barriers and enablers to employment: Black disabled peoples living with Sickle Cell Disorders (SCD)' which is in partnership with Disability Research on Independent Living & Learning (DRILL). Linda was able to contribute to the discussions for this project which aims to identify barriers to employment and produce a guide for employees living with sickle cell.

The Breaking Down Barriers Project also collaborated with the Sickle Cell South London Link to run an Employment and Universal Credit workshop. Hosted by the South London Link and with support from the Citizen Advice Bureau Southwark, the workshop provided lots of information on employment and Universal Credit and gave space for people to ask questions and get more informed.

Events

Hosted by the Hackney Engagement Project, the Breaking Down Barriers

project supported a Yoga workshop run by Simon Owen. The workshop focused on relaxation and was full of tips about dealing with a sickle cell crisis.

On Saturday 12th May 2018, the Breaking Down Barriers Project worked closely with St Mary's Parish and Diane Johnson to facilitate a Community Day for members of the Parrish and local community with information and advice about sickle cell.

Later that month the Breaking Down Barriers Project worked with Willesden New Testament Church of God and Emma Gedeon (a Community Paediatric Specialist Haemoglobinopathy Nurse/Genetic Nurse Counsellor) on their annual health day in order to raise awareness around sickle cell. The Sickle Cell Society working together with Imara hosted a clinical trials information day. The Breaking Down Barriers project went along to support the day and help provide information on the latest clinical trials and research being done.

A Platform for Others

The Breaking Down Barriers project is also keen to provide a platform for people to share their stories in order to encourage others. Linda met with an aspiring sickle cell nurse who lives with sickle cell to hear her story which you can read on our website.

To find out more about the Breaking Down Barriers project or any of the other things which you have read please email linda.chic@sicklecellsociety.org You can also find more information at www.sicklecellsociety.org/breaking-down-barriers/

The Breaking Down Barriers Project's is managed by Alström Syndrome UK and is funded by Sylvia Adams Trust.

GSK IMPACT Award 2018

We have beaten more than 350 organisations from all over the UK to be one of the eight winners of the 2018 GSK IMPACT Awards, a national award that recognises charities that are doing excellent work to improve people's health and wellbeing. We received £30,000 in funding as part of the prize, as well as expert support and development from The King's Fund at a ceremony held at the Science Museum in London on the 17th May, along with seven other GSK IMPACT Award winners.

The award recognises both our community-based services and our influence on national policy. Lisa Weaks, Head of Third Sector at The King's Fund, said: 'One of the impressive things about the Sickle Cell Society is that it is offering services at a community level but is also able to influence national policy. It has been instrumental in establishing national standards for the care of people with sickle cell disorder while ensuring these are firmly rooted in community needs.'

Our other services which were praised include our national telephone helpline which offers support and information, our mentoring scheme for younger people with the condition and our Breaking Down Barriers outreach programme which targets people from Portuguese-speaking and French-speaking communities.

They also noted our guidelines on blood transfusions which we produced in 2016 that focused on improving the experience of people with sickle cell disorder by causing less discomfort and improving efficiency. It is estimated that this could save the NHS £13 million per year. As well as this, they praised our work to improve screening of pregnant women at risk of having a child with sickle cell.

The Society's Chief Executive, John James OBE, said: 'I was absolutely delighted to find out we had won. Over the past five years we think we have been doing great work with patients, their families, and our partners in the NHS, NICE [National Institute for Health and Care Excellence], and industry and so



From left to right: Lisa Weaks (Assistant Director, Leadership and Organisational Development / Head of Third Sector). John James OBE (Chief Executive). Kye Gbangbola (Chair of Trustees). Michele Salter (Vice Chair/Treasurer). Carol Burt (Trustee) Katie Pinnock – (Director, UK and Ireland Charitable Partnerships)

it is really good for that to be recognised.

'It is fantastic recognition that we are doing good work for people with sickle cell disorder, and I am sure it will further enhance our reputation in the sector. For funders it sends the message that we are delivering value for money. The leadership support will also help us to chart the next stage in our journey.'

Developing leaders in the charity sector is an important aim of the GSK IMPACT Awards programme, which has now been running for more than 20 years, and the Society will have access to training and leadership development tailored to our needs. We will also be invited to join the GSK IMPACT Awards Network, a national network of almost 80 award-winning health and wellbeing charities working together to develop their leaders, find new ways of working, and support others.

Thank you to all those who support our work and who work tirelessly to help improve the lives of those living with sickle cell.



Service users Malika and Zaina talk to John James OBE for GSK Impact Award film

our guidelines on blood transfusions which we produced in 2016 that focused on improving the experience of people with sickle cell disorder by causing less discomfort and improving efficiency. It is estimated that this could save the NHS £13 million per year. As well as this, they praised our work to improve screening of pregnant women at risk of having a child with sickle cell.

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Some of the Sickle Cell Society staff celebrate the award



Our Chief Executive, **John James**, is awarded an OBE in the Queen's Birthday Honours

John James, our Chief Executive, has been awarded an OBE for his services to sickle cell disorder and health as part of the Queen's Birthday Honours.

John has had a long and successful career working for the health and charity sector. Prior to working at the Sickle Cell Society he spent 33 years working within the NHS including four CEO roles and becoming the first Black African-Caribbean Chief Executive in the NHS. John has also held senior management and board level posts in Primary Care Trusts, London teaching Hospitals, and Mental Health Trusts. Further to that he served as a senior civil servant for the Department of Health under Professor Sir Bruce Keogh.

For the last five years, John James has been the Chief Executive of the Sickle Cell Society. Under his leadership the Society has

seen significant growth and achievements. The Society recently beat more than 350 organisations from all over the UK to be one of the eight winners of the 2018 GSK IMPACT Awards, a national award that recognises charities that are doing excellent work to improve people's health and wellbeing.

Under John's leadership, the Society has also worked in collaboration with patients and healthcare professionals to publish the 2nd edition of a national set of standards of care for adults living with sickle cell disorder. The standards were recently launched in the Houses of Parliament and aim to continue improvements to care across the UK.

In 2016, the Society worked closely with the National Institute of Health and Care Excellence (NICE) to produce guidelines on blood transfusions that will improve the experience of people with sickle cell disorder

by causing less discomfort and improving efficiency. It is estimated that this could save the NHS £13 million per year.

John has previously received a national NHS Leadership award and his dedication to personal development has continued with the Sickle Cell Society's accreditation against the Investors in People Standard.

Further to his work at the Sickle Cell Society he served on the board of two national Charities as a Trustee and is also a Magistrate.

John James said: "I feel very proud to be receiving this honour and was excited to share this good news with my family, friends and colleagues. I hope that it will help raise the profile of the important work we do as a charity, so that we can continue to support people living with sickle cell disorder and their families."

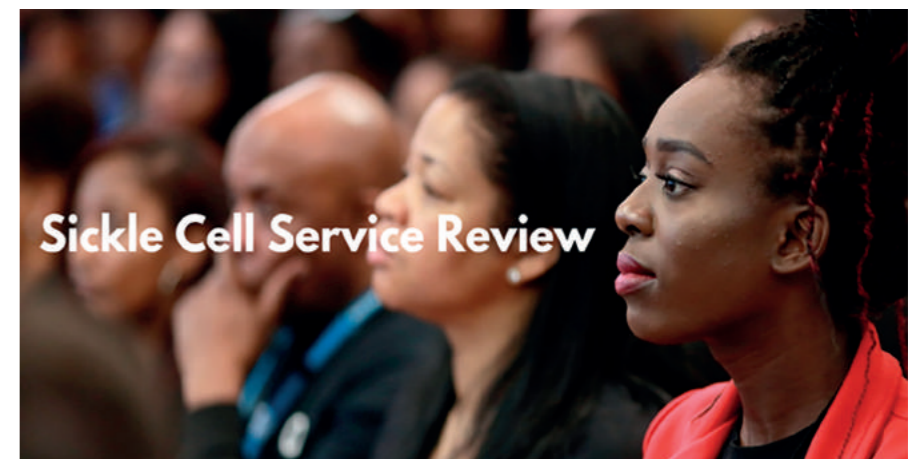
John James OBE

Did you know?

SCD is inherited from both parents; sickle cell trait is inherited from one parent.

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 by doing just that. Kye Gbangbola (Chair of the Sickle Cell Society) wrote a blog for the NHS website, drawing attention to the importance of the NHS Haemoglobinopathies Service Review (Sickle Cell Service Review). We shared a video of our NHS Lead, Iyamide Thomas, being interviewed for Born to Win with Barbara Allen for Faith World TV. During the interview she talked all about sickle cell and the newly published Standards for sickle cell. We ran our 'Did You Know?' social media campaign which focused on educating people on key points about sickle cell. We also shared the various posts and events which people were doing across the country to raise awareness. In the evening we ran a Facebook Live with NHS England to talk about the Sickle Cell Service Review.



Sickle Cell Service Review

In our previous newsletter we discussed the NHS Haemoglobinopathy Review. Commissioned by NHS England, working with the Clinical Reference Group for Haemoglobinopathies and the Sickle Cell Society, the review looked at sickle cell and thalassaemia services.

Over the past three months the Sickle Cell Society has been gathering feedback from patients, carers and supporters about NHS England's planned changes to short and long stay hospital admissions for people with Sickle Cell Disease.

We have received hundreds of responses via our online survey, Facebook Live Q and A, our engagement workshop in Birmingham and at our AGM in London. Thank you to everyone who has shared their views so far.

We are now analysing all the information you have given us and will share our interim findings with you in September. There will be further opportunities to contribute your views on the specific changes planned after this time. We will let you know how to get involved by updating you on our social media and by contacting local Sickle Cell Support Groups.

You can find out more information at www.sicklecellsociety.org/servicereview/

Become a Member

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. Membership entitles you to the following:

- The right to vote at the annual general meeting which takes place in July each year
- Regular newsletters (like this one) to keep you abreast of national developments including policy, service development, research, treatment and ongoing management of the condition.
- Invitation to attend our free events so you can hear first-hand of the work being done nationally and giving you the opportunity to network with others in similar circumstances
- Signposting to sources of support including information, advice and advocacy
- Involvement with patient and carer focus groups related to research and development

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 visit www.sicklecellsociety.org/join-the-society/ and fill out the form to become a member. Alternatively, email info@sicklecellsociety.org to request a membership form.



Sickle Cell Society recognised as an Investor in People

The Sickle Cell Society has been awarded accreditation against the Investors in People Standard, demonstrating our commitment to high performance through good people management.

Investors in People is the international standard for people management, defining what it takes to lead, support and manage people effectively to achieve sustainable results.

Underpinning the Standard is the Investors in People framework, reflecting the latest workplace trends, essential skills and effective structures required to outperform in any industry. Investors in People enables organisations to benchmark against the best in the business on an international scale.

Paul Devoy, Head of Investors in People, said: "We'd like to congratulate the Sickle Cell Society, Investors in People accreditation is the sign of a great employer, an outperforming place to work and a clear commitment to success. The Sickle Cell Society should be extremely proud of their achievement."

For more information about Investors in People please visit www.investorsinpeople.com



Update on the NHS Screening Programme and Patient Societies 'Engagement Project'

By **Iyamide Thomas**,
NHS ENGAGEMENT LEAD, SICKLE CELL SOCIETY

In the last two issues of our newsletter I reported on the two-year collaborative project the Sickle Cell and UK Thalassaemia Societies (i.e. the 'Patient Societies') were doing with the NHS Sickle Cell and Thalassaemia Screening Programme ('Screening Programme') to consult with health professionals and users of the screening pathway in order to improve timeliness of the offers of antenatal screening and prenatal diagnosis to couples at risk of having a child with sickle cell or thalassaemia. The initial project ended on 31st March 2018 and was extended to the end of July. Recently the Screening Programme published a new tender for future work and the Patient Societies have applied.

The two-year project 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. It showed that the Patient Societies can be a very valuable resource for health care professionals. These Societies can work very flexibly within their respective communities and from a culturally sensitive perspective thus gaining trust and very valuable information from their service users. The project's key achievements were that several new resources which contained information and directives for health professionals and service users were produced that would help improve service delivery within the Screening Programme. This was then followed by a stakeholder conference in Birmingham in March 2018.

Key Achievements

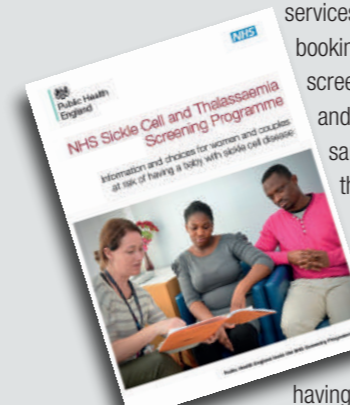
Parents' Stories Booklet

'Parents' Stories - personal experiences of the NHS Antenatal Sickle cell and Thalassaemia Screening Programme' is a publication giving detailed and personal experiences of women and 'at-risk' couples who have been through the Screening Programme within the last five

years. This is available from the Sickle Cell Society or online at:
<http://www.sicklecellsociety.org/resource/parents-stories/>
<http://www.ukts.org/parents-stories.html>

Screening Programme Handbook

This new programme handbook for health professionals contains counselling and referral guidelines for at-risk couples developed using the information from the 'Parents' Stories'. The new guidelines state that antenatal services must provide direct access to maternity services to arrange the first booking appointment and screening must be offered and if accepted, the sample taken, during this first appointment. If a couple is already known to be at risk, for example from already having an affected child or having been identified during a previous pregnancy, they must be



given direct access to specialist counselling services. The handbook is published as an HTML online <https://www.gov.uk/government/publications/handbook-for-sickle-cell-and-thalassaemia-screening>

Screening Programme Leaflets

New leaflets for couples at risk of having a baby with sickle cell or thalassaemia and one describing the test for fathers were produced after a focus group session with service users and project staff. The leaflets now contain clear English without too much technical or medical terminology. These are available online at: <https://phescreening.blog.gov.uk/2017/08/22/evamped-sickle-cell-and-thalassaemia-at-risk-leaflets-published/>

Birmingham Conference

On 21 March 2018 the Sickle Cell Society and UK Thalassaemia Society organised a very successful conference in Birmingham – 'Parents' Stories and Service Evaluation: investigating the causes of late offers of antenatal screening and prenatal

diagnosis' – attended by 65 health professionals, service users and other stakeholders to discuss the results of the two-year collaboration with the Screening Programme and learning and recommendations from the project. Many commented on the impact of the *Parents' Stories* and that the learning from the conference would lead to changes in their own practice and that of their colleagues. Below are some comments from healthcare professionals:

"I hope to use this learning to make a difference"
"The parents' stories will stick in my mind"
"Very informative and enjoyable"

As a result of this collaboration between the Screening Programme and Patient Societies, necessary changes to improve performance have been identified which should ensure that the offer of screening and prenatal diagnosis are made in a more timely way, to enable service users to consider the options and for their decisions to be acted on within the Screening Programme standards.



Sickle Cell Society CEO, John James OBE, summarises the discussion from our successful stakeholder conference held in Birmingham

Look out for the Warm Home Discount Scheme in



October 2018

You could get £140 off your electricity bill under the Warm Home Discount Scheme.

The money isn't paid to you – it's a one-off discount on your electricity bill, between October and March.

You may be able to get the discount on your gas bill instead if your supplier provides you with both gas and electricity. Contact your supplier to find out.

The Warm Home Discount Scheme will start on 15 October 2018.

The discount won't affect your Cold Weather Payment or Winter Fuel Payment.

There are 2 ways to qualify for the Warm Home Discount Scheme:

- you get the Guarantee Credit element of Pension Credit - known as the 'core group'
- you're on a low income and meet your energy supplier's criteria for the scheme – known as the 'broader group'

How you apply for the Warm Home Discount Scheme depends on how you qualify for the discount. If you get the Guarantee Credit element of Pension Credit, you qualify for the discount, if on 8 July 2018 all of the following applied:

- your energy supplier was part of the scheme
- your name (or your partner's) was on the bill
- you were getting the Guarantee Credit element of Pension Credit (even if you get Savings Credit as well)

This is known as being in the 'core group'.

How to apply

You'll receive a letter by 7 December 2018 telling you how to get the discount if you qualify. Your letter will say if you need to call a helpline by 28 February 2019 to confirm your details. Your electricity supplier will apply the discount to your bill by the end of March 2019. Contact the Warm Home Discount Team if you do not get the letter and you think you're eligible for the 'core group'.

The Warm Home Discount Scheme is now closed. The helpline will open on 15 October 2018.

Warm Home Discount Team

Telephone: 0800 731 0214
Monday to Friday, 8:30am to 4:30pm

Warm Home Discount Team

Blue Zone, Ground Floor Phase 1
Peel Park
Brunel Way
Blackpool FY4 5ES

Do not contact the Warm Home Discount Team if you're not eligible for the 'core group'.

If you're on a low income

You may be able to apply directly to your electricity supplier for help if you don't get the Guarantee Credit element of Pension Credit but:

- your energy supplier is part of the scheme
- you're on a low income
- you get certain means-tested benefits

This is known as being in the 'broader group'.

To get the discount you'll need to stay with your supplier until it's paid.

How to apply

Your electricity supplier decides who can get the discount – check with your supplier to see if you're eligible and how to apply.

Check with your supplier as early as possible. The number of discounts suppliers can give are limited.

If you need more information, contact Sickle Cell Society Helpline by emailing helpline@sicklecellsociety.org or calling the helpline on 020 8963-7794 (Mon-Friday excluding bank holidays, 10-5pm).

AGM 2018



Lead mentor, June Okochi discussing the Mentoring Scheme



Nathan Ampofo-Anim asking a question



Reading over the Annual Report



Feeding back on the Sickle Cell Service Review

On the 21st July we held the 39th Annual General Meeting at De Vere Grand Connaught Rooms in Central London. The official part of the AGM began with an introduction from our Chair Kye Gbangbola, a look at the audited accounts by Vice Chair and Treasurer Michele Salter and an informative Q and A.

After a delicious lunch we had a short message from Professor Simon Dyson about the latest study on employment. This was followed by a presentation by the Hackney and City Mentoring programme as well as talks from the mentees.

We were then joined by Senior NHS England Commissioner, Claire Forman, who

presented the proposed plans from the Sickle Cell Service Review before having table time to get service user feedback and suggestions.

We then had an award presentation to congratulate the winners and runners-up of the Black on Black Award, Emmanuel Amuta Poetry Award, Floella Benjamin Award, and Dr Ade Olujuhongbe Award (read more about the

awards on the next page).

It was great to have such a packed room and to see so many of our members. Thank you to everyone who came. We had a brilliant day and would love to see you at our 40th AGM next summer.

You can see more pictures from the AGM at: www.sicklecellsociety.org/agm18/

Awards

As part of our 2018 AGM we announced the winners of our four awards. Congratulations to all the winners and runners up. The awards were all well-deserved and show the range of talent and determination we have in the sickle cell community.

Dr Ade Olujohungbe Award

This award is in memory of Dr Adebayo Olujohungbe: an NHS Consultant Haematologist and former Medical Adviser to the Sickle Cell Society, who provided leadership and determination in developing Adult Standards of Care for Sickle Cell. It recognises a health professional or adult sickle cell team who has made significant improvements or provided high quality care for adults with sickle cell disorder. Joint winners: **Matty Asante-Owusu and Dr Sara Stuart-Smith**
Runners up: **Dr Marie Donohue and Dr Srinivasan Narayanan**



Matty Asante-Owusu



Dr Marie Donohue



Dr Srinivasan Narayanan

Black on Black Award

Established thanks to our Patron, Trevor Phillips 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 disease. Winner: Laurel Brumant-Palmer
Runners-up: **Noel Gordon and Jenica Leah**



My Journey by Laurel Brumant-Palmer



Noel Gordon



Nora Molongwe



Nathan Ampofo-Anim

Floella Benjamin Award

Established by another Patron, 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 a Sickle Cell Disorder. Joint winners: **Nathan Ampofo-Anim and Nora Molongwe**

Emmanuel Amuta Poetry Award

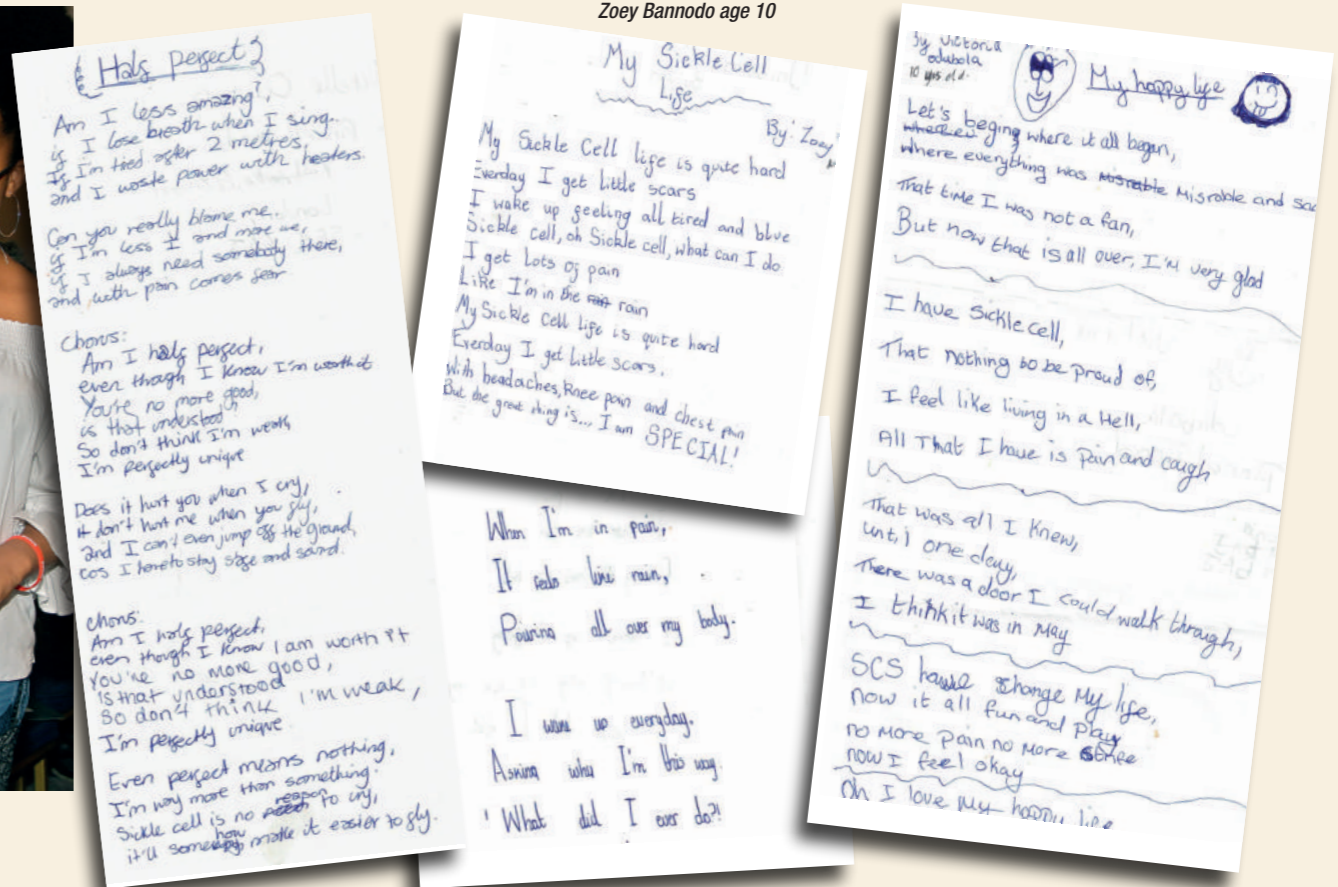
The Emmanuel Amuta Poetry award has been created in memory of Emmanuel Amuta who suffered from sickle cell and sadly passed away on 19 September 2017, age 14 years. Emmanuel was a confident, caring and gifted young man most cherished by the Sickle Cell Society. He was good at poetry and rap and really endeared himself to participants at the Society's AGM in July 2016 when he narrated his poem 'A Beautiful Cell'. This award will be his fitting legacy. The award is for a young person between ages 10 – 15 years for a piece of poetry. Winner: **Michelle Odubola**
2nd Place: **Victoria Odubola**
Runners up: **Zoey Banado and Rhianna Abassah**



Michelle Odubola Age 12



Victoria Odubola Age 10



Wales Patient, Carer and Family Education Day

On Saturday 2nd June we teamed up with Friends of Cardiff Sickle Cell and Thalassaemia, UKTS, Cardiff and Vale and Wales Gene Park to host a patient education day. Chaired by our patron Professor Dame Elizabeth Anionwu the day kicked off with a spectacular performance by Bethal Choir Cardiff. Elizabeth then talked us through the progress that has been made so far, highlighting the significance of both Windrush and the NHS. Our chief executive, John James OBE, then talked about how to maintain high

service standards across the country by working together with patients. This led nicely on to a talk by Faith from Friends of Cardiff Sickle Cell and Thalassaemia who shared various patient perspectives on the current services in Wales.

Ben Player from All Wales Medical Genetics Services then spoke on the implications on inheriting sickle cell and thalassaemia from a genetic point of view. Elaine Miller from UK Thalassaemia Society then talked about the need for genetic counselling.

Dr Jonathan Kell explained the role of Cardiff and Vale University Health Board in improving services. Then Dr Sian Lewis, managing director of Welsh Health Specialised Services Committee (WHSSC), talked about their role in improving care.

Dr Indu Thakur, Paediatric Haematologist,

Noah's Ark Children's Hospital gave a very powerful talk on what is and what is not happening in children's services. She highlighted that many 16-18 year-olds find themselves in no man's land and emphasised the need for improvement.

With improvement on people's minds, Senior NHS England Commissioner, Claire Foreman, gave a presentation on how specialised services are commissioned in England before there was a chance for attendees to feedback through table discussions.

The day concluded with another excellent performance from Bethal Choir Cardiff.

We are grateful to all those who presented and to all those who attended. Keep an eye on our website and social media channels for other patient education events.



Self Over Sickle

In our last newsletter we introduced our Patient Education and Training Lead and the new project funded by Bupa UK Foundation as part of the Healthy Futures funding programme. That project has taken on the name Self Over

Sickle (SOS) and looks to promote improved physical, psychological, social and emotional wellbeing, primarily for young people aged 16-25. Focusing on areas of transition from moving away from home and dating to pursuing a career and raising a family, the sessions are entwined with games and creative activities to practically and positively impact all who attend.

Taking place across weekday evenings, spanning the East and West Midlands, Manchester, Yorkshire and South London, sessions are open to those who live locally and those willing to travel. Topics to look out for include:

- ★ Body Goals – For tips and tricks on how to stay well this winter
- ★ Life Goals – For the know-how on travelling,

getting a job and going to university

- ★ Career Goals – Employment or entrepreneurship? Find out the pros and cons of each
- ★ Relationship Goals – Discuss dating, family planning and communicating your condition
- ★ Squad Goals – Get to grips with the support in your local area
- ★ My Goals – Learn to own your condition and boost your mood
- ★ You can find out more about the project by visiting

www.sicklecellsociety.org/selfoversickle/ or by emailing siann.millanaise@sicklecellsociety.org



Hackney and City Mentoring Programme

It has been a busy few months for the Hackney & City Young Persons Mentoring Programme, as it continues to grow from strength to strength. Mentors Michael, Whitney and June have worked hard to identify and overcome some of the challenges faced by young people living with sickle cell. Some of the key focuses have been on helping mentees to cope with education and putting in place effective academic support, helping mentees to understand how to manage sickle cell independently and how to effectively handle the transition from paediatric to adult care. The mentors have also helped to celebrate some of the key milestones and accomplishments of the mentees, which have so far included seeking and securing work placement opportunities and reaching long-term personal goals. Mentees themselves have commented on how the mentoring has "helped a lot in my school activities, especially with my university choices and general advice" and that one of the biggest benefits has been learning "how not to put so much pressure on myself".

In April, Michael and June attended the East London & Essex Sickle Cell Network Meeting along with some of the current mentees who shared their experiences of sickle cell and how they have found the mentoring programme. One mentee explained that "the program has

inspired me educationally to find out and write about sickle cell and to create awareness" and that "it has truly been an unforgettable experience". She also described how "emotionally, it has helped me gain confidence in myself, which in turn has helped me put myself out there". In May, Whitney and June attended the official launch of Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK. At the launch June shared her experiences as a member of the Editorial Board and also as a patient, while Whitney shared her hopes for what the new standards will achieve



Mentors June, Michael and Whitney

from her perspective as a patient and as a mentor.

The mentoring programme has been in high demand the last few months, which has proved testament to the great need for support for young people living with sickle cell. From general guidance and advice, to providing practical solutions, the mentoring programme highlights the benefits of peer-to-peer mentoring between those who share similar



Mentors June and Whitney at A Solace Support Group meeting

experiences and perspective. Given the successful uptake and demand of the mentoring programme and the high level of engagement with both parents, young people and clinicians the mentors are now seeking to demonstrate how the programme could successfully be extended for children and young people living outside of the City & Hackney.

The mentors shared more information on the mentoring programme at the Sickle Cell Society AGM in July. Mentees also attended to share their experience of the programme and how they have benefited from having a mentor. To hear more about mentoring, please feel free to reach out to the mentors directly on mentors@sicklecellsociety.org



June Okochi at a mentoring session

Sickle Cell and Thalassaemia All-Party Parliamentary Group

As well as organising the launch of the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK*, the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG) has been very busy with a new report.

“How Did You Contract That?”

SCTAPPG report into the institutional failures of Personal Independence Payment (PIP) for those living with sickle cell disease and thalassaemia. The title of the report is a question which was asked by a medical assessor to a 46-60, sickle cell patient from London.

Initial conversations took place regarding service users mounting concerns of the Personal Independence Payment (PIP) process

at the SCTAPPG meeting on November 15th 2017. Both voluntary organisations (Sickle Cell Society and UK Thalassaemia Society) shared that it was clear that the regularity of service user concerns coming through to helplines indicated a system that was failing patients and exacerbating the difficulties they faced.

Discussions centred on the strongly held sentiment that service users believed that their condition, and the lack of understanding around it, from the outset put them at a disadvantage.

It was decided that the SCTAPPG go forward with this as a potential topic, and collect evidence to substantiate these claims. The SCTAPPG through this report has endeavoured to capture those recommendations made at the November meeting and the voice of the



The All-Party Parliamentary Group for Sickle Cell and Thalassaemia launching the report: ‘How did you contract that?’

membership of both the Sickle Cell Society and the UK Thalassaemia Society.

We are pleased to announce that the report has resulted in extended dialogue with the government. The SCTAPPG, with its Chair Rt Hon Diane Abbott MP, have held a meeting with

Esther McVey, Secretary of State for Work and Pensions; Sarah Newton, Minister of State for Disabled People and DWP officials who have reacted positively to our recommendations and we look forward to working with them to enact change. In addition, our patron, Lord Boateng has looked to apply pressure to the government in the Lords with numerous interventions outlining the need for change. The SCTAPPG are scheduled to meet DWP officials in order to overhaul the existing knowledge base on sickle cell and thalassaemia. This we hope in the long run will translate into assessors having the adequate understanding of sickle cell disease and thalassaemia, so henceforth they can make informed decisions on a claimant’s case.

You can read the full report on our website at www.sicklecellsociety.org/pip-report/

Thank you to all those who completed our PIP survey and enabled the production of this report. You can follow the progress of the report at www.sicklecellsociety.org/sctappg/ For more information please email adam.lloyd@sicklecellsociety.org

In memory of Simonne Kerr



At the official opening of the memorial garden in memory of Simonne's son, Kavele. [From left to right: Jenica Leah (Children's Author), Dawn Butler MP, Simonne Kerr, Professor Dame Elizabeth Anionwu (Patron), John James OBE

Everyone at the Sickle Cell Society was deeply shocked and saddened to hear of the death of Simonne Kerr. A long-time member, dedicated volunteer, friend, and recently qualified sickle cell nurse, Simonne was passionate about helping others and will be deeply missed. Police were called to a house in Battersea where she was killed on Wednesday afternoon.

Having lived with sickle cell trait and raising a young child, Kavele, with sickle cell disorder, Simonne was dedicated to raising awareness of sickle cell and the importance of blood donation. She was a hard-working member of the Society who volunteered her time to help fundraise and to help run our annual children's holiday.

In October 2015 her son, Kavele, sadly died from complications of sickle cell. Kavele's school, Leopold Primary School organised a memorial garden for Kavele. The garden, opened in 2017, was a quiet space for children to reflect and receive counselling. Simonne and the school also raised funds to support the Society in memory of Kavele.

We were all delighted when Simonne recently graduated as a registered nurse and started her NHS nursing career in the field of haemoglobinopathies. She loved her job and had a bright career ahead of her.

Simonne was also a very talented singer and a member of the Britain's Got Talent finalist choir, B Positive. Through their spectacular music, B Positive, also raised awareness of the important issue of sickle cell blood donation. The choir's beautiful music and positive message are a testament to each of its members.

We are so grateful for all support and friendship Simonne has given us and for her passion for improving the lives of people living with sickle cell and their families. She will be deeply missed. Our sincere condolences go out to her friends and family.

You can join us in honouring Simonne's memory and supporting her family by donating to the Simonne Kerr Memorial Fund. The money you give will go to help her family at this difficult time. You can donate at:

www.justgiving.com/campaign/simonnekerr/



Kavele Kerr-Campbell Memorial Garden opening

Headstone Fund for the late Cllr Tayo Oladapo

A huge thank you to everyone who contributed to the Headstone Fund for the late Cllr Tayo Oladapo. It's two years now since we had the shock of the late Councillor Tayo Oladapo's untimely death aged 34. We have now raised 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 LB Brent and beyond.

Temitayo Oladapo, born 7th March 1981, studied at Kingston University and was aiming to become a journalist when he was selected to stand as a Labour Party candidate for Kilburn Ward, LB Brent in 2008. Bringing political passion and people skills, Tayo helped connect

the local party branch with young people in the community, working closely with the local police as well as housing and other council officers to help improve family lives in Kilburn. Once elected to represent Kilburn in 2010, Tayo worked tirelessly for local people, taking up problems around the Kilburn High Rd and chairing Brent's local Area Consultative Forum

while he had by then joined the Civil Service. Sadly, he became ill in 2014 and in spite of fighting for his life undergoing a liver transplant, he passed away on 29th January 2016.

With his family living in Nigeria and the USA, the Brent Labour Group helped make funeral and burial arrangements with Co-op Funeralcare. The Sickle Cell Society provided the family and friends with expert support and understanding, helping us through difficult times and giving some context to the effects of Sickle Cell Disorder on Tayo's young life. The Society also commemorated him as an example of holding public office, albeit suffering from bouts of sickle cell disorder, to help inspire others with the disorder to be aspirational.

On the 13th June the Society met with friends and colleagues of the late Cllr Tayo Oladapo at The Granville in South Kilburn to share memories of Tayo and discuss the importance of raising awareness of sickle cell. The meeting was arranged by Mary Arnold who has been at the forefront of the fundraising campaign. Work has now begun on the headstone and we would like to thank everyone who made that possible.



From top left, clockwise: Ben Ogunro (formerly Kilburn cllr with Tayo 2010 – 2014), Joseph Awosika, Merle Barrateau, Joe Jacobs, Mary Arnold, Matthew Neal (Sickle Cell Society), Stephane Goldstein, Mary O'Connor [front], Michael Adeyeye [front left] (formerly Queens Park cllr 2010 – 2014).

Sam Ovuorie

Sam was being treated for malaria when he was first diagnosed with Sickle Cell disease at the age of five years. He was seen at his local hospital for the first time in September 2007 after he presented with pain in both elbows and his right shin which had started three days before. Sam had a history of multiple crises per year, usually affecting his elbows, ankles, thighs and lower back, his pain was controlled using analgesics including morphine, diclofenac and paracetamol. During a crisis, Sam would normally be admitted to hospital for five days or more which would have a huge impact on him, disrupting his school attendance, academic record and ultimately his quality of life.

Sam was referred to NHS Blood and Transplant's Therapeutic Apheresis team in Oxford for Automated Red Cell Exchange treatment when he was just 13 years old. At this point Sam was suffering with excruciating pain in his joints, walking with crutches and frequently in and out of hospital due to the effects of Sickle Cell crisis. He was unable to lead a normal life and was struggling to attend school.

Sam attends the therapeutic unit in Oxford for his treatment every 6-8 weeks. The procedure, which takes about 2 hours, removes Sam's abnormal blood cells and replaces them with donated red blood cells.

Sam is now 21 years old and studying mathematics and economics at University College London. He is very active and enjoys swimming and cycling; last year he climbed Kilimanjaro!

Sam said: "With just six days per year of planned treatment each year, I have had no Sickle Cell crises since starting regular exchange. I used to miss at least ten days of school per month. I have now hiked in Africa in World Challenge, have a completely changed, near normal life and can have high aspirations because I am confident I will be well!"

Additional information:

Therapeutic Apheresis treatment uses a cell separator machine to add or remove constituents of the blood, such as red cells, white cells or plasma. A procedure tailored to the patient's needs can treat many other diseases such as cancer and nerve conditions.

NHS Blood and Transplant provide therapeutic apheresis services to adults and children across England. Treatment is provided by teams of expert nurses and doctors who provide both elective and emergency (24/7 365 days per year) treatment to patients. For more information on therapeutic apheresis services or on how to access treatment please visit our webpages:

<https://www.nhsbt.nhs.uk/what-we-do/diagnostic-and-therapeutic-services/therapeutic-apheresis/>

Approximately 60% of all Sickle Cell patients in England require a special type of blood product called Ro subtype. On average, 8 units of blood (adults)/7 units of blood (children) are used to support every Automated Red Cell Exchange treatment. NHS Blood and Transplant are urgently trying to recruit more black donors to support patients with Sickle Cell. One blood donation takes approx. one hour from start to finish and can save up to three lives. If you or your family would like to donate, please visit www.blood.co.uk



Sickle Cell South London Link – Volunteer Networking and Recruitment Event



The Sickle Cell South London Link held a Volunteer Networking and Recruitment Event in April. The event was aimed at giving existing volunteers the opportunity to meet and network with other volunteers as well as to recruit new volunteers.

A relaxed atmosphere was set from the beginning by entertainment given by a SCS member, Ade Aluko, who did a stand-up comedy set. Two of our existing volunteers spoke about their experiences volunteering. Angela Udeh spoke about volunteering as a blogger and Kike Aderibigbe spoke about volunteering at children activities and adult workshops. Both were warmly welcomed.

To continue with a relaxed atmosphere and to encourage networking they held a competition where attendees had to talk to as many people in the room, asking them specific question listed on a sheet, noting down a response from a set of answers.

The person who had spoken to the most people was to be the winner but it was found that although all the attendees spoke to quite a few people some were engrossed in conversations and therefore had less answers. Therefore, first and second prize winners were drawn from a dip. First prize was two tickets to see a drama play called

Eggshells and second prize was a DVD of The Family Legacy which was produced with the support of the Society.

The attendees were encouraged to complete two questionnaires, one about volunteering and another on the event before they left. This also gave the attendees additional time for socialising.

Other Events

The Sickle Cell South London Link has run a whole host of events over the last few months. They ran the third in their three-part series on support groups. The workshops served to help those who attend, run or want to start support groups to grow and strengthen them. The latest workshop focused on capacity building and joint working.

The South London link also ran a Pain Management workshop which provided advice and information on the different ways to manage pain.

Their Employment and Universal Credit Workshop focused on empowering people with sickle cell by providing them information and giving them a space to ask questions.

They also ran a workshop dedicated to teenagers.

To find out more about the Sickle Cell South London Link visit:

www.sicklecellsociety.org/scsl/



New Sickle Cell Disease Clinical Trials in the UK

On the 3rd June and 14th July we partnered with Imara Inc to run events on the latest sickle cell research. Despite years of research and development, treatment options for patients with sickle cell disease remain limited. More recently, companies and researchers have started to develop new therapies to help improve patient lives. Clinical studies help researchers better understand a disease and how best to treat it, with the ultimate goal to develop new treatments for patients. On both days, patients, carers, family members and healthcare professionals came along to learn about the research which has been done so far. There were also talks on the ongoing trial of IMR-687. The talks covered the scientific data and gave more information about phase 1 and 2 of the trial. There was also an opportunity for patients to ask questions about the trial and research more generally.

Congratulations to Baroness Floella Benjamin



Massive congratulations to our wonderful patron, Baroness Floella Benjamin for being a finalist in the Parliamentary Photography Competition. She kindly donated the prize money to us! Here she is receiving the prize from Matt Hancock, Secretary of State for Culture, Media and Sport.

FUNDRAISING SPOTLIGHT



A huge thank you to the pupils and staff at Burlington Danes for raising £88.98



A big thank you to Marcia Billy and all who attended the SCA/Essity fundraising and awareness event for raising £1000



Thank you to everyone at the TUC 2018 Black Workers conference at Congress House who visited our stall and donated.



A big thank you to Khloe, Danielle & Karen who raised £354.34 running the Manchester 10K.



We are very excited to be nominated Charity of the Year by Imperial College Healthcare DHL GB! They have already raised £100 for us!

A massive thank you to Robert Lorenz for running the Hillingdon Half Marathon and raising £455.62

A big thank you to J Oni for donating £500

A big thanks to Pastor Audrey Eccleston for raising £519.61!

Thank you to TPO Mobile for raising £457.57 for the Society

A big thank you to The John Roan School for raising £201.46

A huge thank you to Cherelle Skeete and Blacktress UK for organising a screening of Black Panther at the Peckham Plex and raising over £400 for us!

A big thank you to dedicated supporter and fundraiser Lucreta La Pierre for raising £543.46 at a performance of Frenemy at The Broadway Theatre in Catford. Thank you also to Bagga John for allowing us to fundraise.

A massive thank you to all our Facebook Fundraisers (April to July) with special mention to Robert White and Professor Dame Elizabeth Anionwu who both raised over £1000.



A huge thank you to John Regis and all those who attended the John Regis Golf Day in Cyprus. Altogether they have raised over £3000 for the Society!





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/become-a-member
www.sicklecellsociety.org/donate
Charity number: 104 6631
Sickle Cell Society, 54 Station Road, London NW10 4UA
Telephone: 02089617795

www.sicklecellsociety.org

