

Winter 2017/2018

# Sickle Cell Newsletter



SICKLE  
CELL  
SOCIETY



## In this issue:

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- Children's Holiday 2017 (and how to sign up for 2018)
- The new Hackney and City Mentoring Scheme
- Plus, so much more...

[www.sicklecellsociety.org](http://www.sicklecellsociety.org)

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## Message from John James and Kye Gbangbola



2017 has been a positive year. Despite austerity, uncertainty and lots of challenges in securing funding we have seen continued growth and many success stories. The Society has continued to grow, with more members, more volunteers and more staff. There are lots of things to celebrate and reflect on as you will see in this newsletter.

The overall message from this year has been that of hope. In September we partnered with The Royal Society of Medicine to run the Medicine and Me patient and clinician conference. The conference gathered patients, carers and clinicians to hear about the latest research and clinical trials and to hear the views of those who are living with sickle cell. Dr Jo Howard, chair of the UK forum and consultant haematologist, gave a fantastic talk on clinical trials and we saw the many different options for treating sickle cell which are now being developed. It was exciting to see the range of treatments which were being worked on and the hope that it brings to those living with sickle cell.

We are also excited to be producing a new set of national standards for the clinical care of adults living with sickle cell. We released the previous standards in 2008 so it is great that we have been able to update them. We hope that these standards will help create a better and more equal level of care for every person living with sickle cell across the country. Keep an eye out for when they are released.



This coming year there will also be a NHS haemoglobinopathies review. The review will be looking at how to improve and shape the specialised services which sickle cell falls under. We are working closely with NHS England on this review and there will be a public consultation during which you will be able to share your opinions. We have more information about the review in the newsletter so read on to find out more.

There have been so many encouraging things to happen over this past year and none of them could have happened without the hard work and passion of our staff, volunteers, trustees, patrons, supporters, partners and all of the hard working support groups up and down the country. This year has really shown us that the sickle cell community is just that, a community. We look forward to building on these achievements in 2018.

With best wishes for the New Year,

*John James (Chief Executive) and Kye Gbangbola (Chair of Trustees)*

# NHS

## Haemoglobinopathy Review

NHS England, working with the Clinical Reference Group for Haemoglobinopathies and the Sickle Cell Society have commissioned a review of Haemoglobinopathy services (sickle cell and thalassaemia) across England. The review will look at how sickle cell and thalassaemia services can be improved for the future. At this early phase in the plans, focus groups with patients and families were held in London, Birmingham and Manchester.

The Society want to make sure that all individuals living with sickle cell and their families get to have their say. When NHS England publish their plans for public consultation, the Society

again will be organising meetings across the country, to ensure that patients and families can have their say about the proposals for improving services. This is a once in a generation opportunity to shape the services people with SCD could receive. To keep updated with when the meetings will be please follow our social media channels or keep an eye on our website.

If you have any questions or would like to be emailed with updates about the meetings then please email [matthew.neal@sicklecellsociety.org](mailto:matthew.neal@sicklecellsociety.org)

## The Importance of Taking Daily Medication Shown in New Study of Newborn Screening

Researchers from King's College London have recently published findings of the newborn sickle cell screening programme in England (2010-2016). The screening programme, which has been running since 2002, works to identify newborns with sickle cell. This early identification means that newborns can receive the treatment they need as soon as possible. The treatment is to prevent severe infections. It is called penicillin prophylaxis and means taking penicillin medicine every day. Parents and carers are also offered education and support to help them to care for their child and know when they need medical care.

The findings show that the screening programme is mostly working well in identifying newborns with sickle cell and ensuring they get the care they need. One of the key things which it also reinforced was the importance of taking penicillin. Another research publication\* shows that children living with sickle cell disease remain at an increased risk of infections such as Invasive Pneumococcal Disease (IPD). IPD can be prevented and treated in newborns through the taking of penicillin. Together, the two bits of evidence show how important taking penicillin medication every day is for the wellbeing of newborns and children.

It is great to see how effective the screening programme has been but it is only the first part of care for children with sickle cell. A collaboration between health professionals and parents/ carers to ensure children regularly get and take penicillin is key to reducing infection and death.

Dr Allison Streetly, lead author of the evaluation from King's College London said: "The NHS newborn screening services have achieved outstanding results for both test performance and bloodspot uptake. We should celebrate this achievement and ensure that standards are maintained. There is more to do to achieve optimal follow-up of infants with fail-safe and further efforts are needed to ensure parents are supported so that babies receive all appropriate preventive interventions, including daily penicillin and vaccination which saves lives."

The Archbishop of York, the Most Reverend John Sentamu, a friend and supporter of the Society, said: "I commend the publication by King's College London because it shows us the effectiveness of the newborn screening programme whilst emphasising the need for penicillin for children living with sickle cell. Regardless of if you are a person of faith or a person of no faith, this research shows the importance of penicillin for the wellbeing of children living with sickle cell disease."

The results were published in Archives of Disease in Childhood and links to them can be found on our website.

\*Risk of Invasive Pneumococcal Disease in Children with Sickle Cell Disease in England: A National Observational Cohort Study, 2010-2015

# 2017 AGM

In July we held our 38th Annual General Meeting at Holborn Bars in central London. The AGM was well attended and it was great to see so many members come together to talk about the Society. As well as the usual AGM discussions around the Society's progress throughout the year there was also a talk on opioids by Dr Paul Telfer and on Sickle Cell Pain and Complementary Treatment by Dr Kofi Anie. There was also a long and informative Q and A. The 39th AGM is on the 21st July so put the date in your diary and keep an eye out for how to register. We would love to see you there.



# Terrific Teens Sickle Cell Digital Storytelling Workshop

In October 2017, 23 young people, parents and siblings gathered at beautiful Roffey Park in Sussex to create digital stories about their experiences of living with sickle cell disease. 'Terrific Teens!' is the brainchild of Dr Claudia Gore, a paediatric allergy consultant, who obtained funding from Imperial College Charity and the Northwest London CLAHRC for the project. The workshops were facilitated by Patient Voices ([www.patientvoices.org.uk](http://www.patientvoices.org.uk)), who have been helping people create short videos about their experiences of healthcare since 2003 in order to give clinicians and decision-makers a chance to walk in the shoes of people who deliver and receive healthcare.

During three days, workshop participants drafted scripts, recorded voiceovers, found or took photos and then edited their own short videos. Rita Fyneface, who was there with her daughter, Caroline and son Julian had this to say: 'It was a once in a lifetime experience,' while Caroline commented that she intended to use her story 'to help doctors understand how to treat people with sickle cell better'. Rita showed her story at a national NHS conference on 7th December; the stories are available at [www.patientvoices.org.uk/terrificteens.htm](http://www.patientvoices.org.uk/terrificteens.htm)

By Dr Pip Hardy, Co-founder, Patient Voices Programme



# Warwickshire Golf Day

A huge thank you to Orbit Homes for organising the Annual Charity Golf Tournament at The Warwickshire Golf and Country Club. John had a brilliant time and we are very grateful that they raised a massive £23,727.08 for the Society. Thank you!



# Medicine and Me



In September we teamed up with The Royal Society of Medicine to run the Medicine and Me Patient Education Conference.

Medicine and Me is a series of meetings run by The Royal Society of Medicine designed to educate and update everyone on various medical conditions as well as giving a voice

for patients and carers to share their concerns and thoughts on treatment, management and care.

The audience on the day consisted predominantly of those living with sickle cell disorder as well as their carers and family. There were also clinicians and researchers.

The event was kicked off by Kaji Sritharan, the Associate Dean of the Royal Society of Medicine and was followed by a very informative talk by Dr Jo Howard on what sickle cell is. We then had one of the three patient perspectives. The patient perspective talks were given by Whitney Joseph, Chantelle Pierre and Lynette Adjei and gave us a vital insight into what it means to live with sickle cell and the issues that people face day to day.

The next talk was done by Dr Shivan Panoram and was about how to best manage pain. We had another patient perspective before Dr Kofi Anie discussed the psychological aspects of sickle cell disorder. The final patient perspective led us into a talk by haemoglobinopathy specialist nurse, Keisha Osmond-Joseph on transitioning from child to adult care. Dr Jo Howard then looked towards the future by discussing the various clinical trials and research which is going on.

John James finished up by highlighting how and where you can find help and support before the event came to a close with a panel discussion.

The event was a big success with lots of important information being learnt and plenty of opportunities to hear the opinions of those living with sickle cell.

You can view all of the talks on the Royal Society of Medicine website by searching Medicine and Me: living with sickle cell disease.



# NHS Sickle Cell and Thalassaemia Antenatal Screening: What Parents Think

By Iyamide Thomas – NHS Engagement Lead

For couples of African, Caribbean, Middle-Eastern, Asian or Mediterranean origin who might be at increased risk of having a baby with sickle cell or thalassaemia, two serious genetically inherited blood conditions, it can be a very worrying time. England has a National Health Service Sickle Cell and Thalassaemia Screening Programme (NHSSTSP) offering all pregnant women antenatal screening for sickle cell and thalassaemia. If the woman is a 'carrier' (or 'trait') the baby's biological father is invited too. (The NHSSTSP also offers newborn screening for sickle cell). Antenatal screening enables parents to make informed choices based on information about the baby's risk of inheriting sickle cell or thalassaemia, e.g. if both parents are carriers there is a 25% chance their baby could be born with one of the conditions. Timing is crucial to making informed choice so NHSSTSP has prioritised improving the offer of screening to the mum-to-be so it is by 10 weeks of pregnancy and improving the offer of prenatal diagnosis (PND) - a diagnostic test done on the foetus in the womb - so it is by 12 weeks and 6 days of pregnancy.

To determine any barriers affecting the timeliness of screening and PND offers and recommend ways of improving services, the Screening Programme worked jointly with the Sickle Cell Society (SCS) and UK Thalassaemia Society (UKTS) on an 'engagement project'. Elaine Miller of the UKTS and I conducted structured interviews with parents at risk of having a baby with sickle cell or thalassaemia, who volunteered to share their personal experiences of going through antenatal screening within the last five years.

## What Parents Said

Most women had told a healthcare professional (usually their GP) about their pregnancy early on and already knew their sickle cell or thalassaemia status before becoming pregnant. Most fathers also knew their status. Parents said some healthcare professionals did not have much knowledge of the conditions or the screening pathway and did not recognise the need for prompt referral to counselling and PND.

"Although we were given the wrong advice by the GP, once we were referred to the Sickle Cell and Thalassaemia Centre we had excellent support. The counsellor spent a long time with us explaining about the risk to the baby and also about how thalassaemia can be managed." (Couple at risk of having a child with thalassaemia).

Some women were given wrong information or experienced delays. They wanted prompt referral, or 'self-referral', to specialist nurses and midwives at the Sickle Cell and Thalassaemia Centres as from their experience this sped things up.

"Both pregnancies were reported to my GP and I booked the midwife online as instructed. Appointments were quick and bloods were done within ten weeks. The midwife referral to the sickle cell centre for the first pregnancy was delayed by paperwork however for the second pregnancy the midwife told me to contact the centre myself so things could move quicker and they did" (Mother at risk of having a child with sickle cell).

## Parents also wanted:

- examples of positive outcomes for affected children
- referral to patient organisations who could find someone in the community to support them
- to meet individuals who were living successfully with the conditions

## What Happens Next?

These parent stories are an invaluable resource for people commissioning services and working in the NHSSTSP and have contributed to a report with recommendations for community organisations, the public and screening providers.

The public should keep presenting early in pregnancy or contact maternity services or specialist counselling services directly. They should also tell healthcare professionals that they want counselling and prenatal diagnosis and not assume that all healthcare professionals will know what they want.

"I am so grateful to those who have been willing to share their stories to make this happen. I am struck by the improvements that exist already between my experiences between 1997 and 2005 and those of the parents featured in the study. A very emotional read but in the context of the comprehensive discussion and guidance surrounding it all, one can be hopeful for the successful implementation and the improvements which will no doubt follow and will benefit our children in the future". (Lynette – Project Advisory Group member with two children with sickle cell)

Elaine and I would like to thank the volunteers who shared their stories without which we will never have obtained such rich evidence.

For the full 'Parent Stories' go to:

<https://tinyurl.com/parent-stories-sickle-cell>

If you would like to order hard copies of the 'Parent Stories' booklet please email: [info@sicklecellsociety.org](mailto:info@sicklecellsociety.org)

Sickle Cell Society: [www.sicklecellsociety.org](http://www.sicklecellsociety.org)

UK Thalassaemia Society: [www.ukts.org](http://www.ukts.org)

NHS Sickle Cell & Thalassaemia Screening Programme: <http://sct.screening.nhs.uk/>

NHS Choices comprehensive website on screening:

<https://www.nhs.uk/conditions/pregnancy-and-baby/screening-sickle-cell-thalassaemia-pregnant/>

# Say hello to our new staff, trustees, and patron

Since the summer we have had a big change of staff. We have had to say goodbye to Jessica, Kalpna, Zoe, Craig, and Blaire and are welcoming in six new members of staff:

Matthew Neal – Communications and Social Media Officer

John Phelps – Head of Fundraising

Tracy Williams – Hackney Engagement Officer

Adam Lloyd – Parliamentary Officer

Grace Adejuwon – Children's Activities Coordinator

Siann Millanaise – Patient Education and Training Lead

## We also have been joined by two new trustees:

### Carol Burt

Carol is a highly experienced Health and Social Care Professional with Executive-level expertise. Carol is currently a Director for a Learning Disability Residential Home, SCIPE CIC a community engagement organisation, a Non-Executive Director for Healthwatch Birmingham and sits on a number of local committees. This year she had the opportunity to be appointed as a Public and Patient Voice for the Haemoglobinopathies Clinical Reference Group Specialised Commissioning NHS England. She has lived experience of caring for her son with Sickle Beta-thalassaemia.

## Ganesh Sathyamoorthy

Ganesh is the Assistant Director for Partnership and Business Development at the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care North West London (CLAHRC NWL). He currently leads the development of strategic partnerships between NHS organisations, universities, industry, third sector and other NIHR family organisations.

## We are delighted to welcome a new patron to the Society:

### Kym Mazelle



Credited as 'The First Lady of House Music', Kym has an extensive and successful history in the music industry. She pioneered the genre in the UK and has collaborated with some of the most talented musicians in the world. Kym recently celebrated 30 years of soulful vibes by performing a concert at The Hideaway in South London.

# A Better Response to a Crisis

The London Ambulance Service released a new set of standards this July which will improve the level of care for sickle cell patients as well as many others. Previously, many people living with sickle cell had reported having to wait an unacceptable amount of time for an ambulance when calling in for a sickle cell crisis. The New Ambulance Response Programme standards however, place having a sickle cell crisis into category 2; a response time of 18 minutes (mean response time). Patients with known sickle cell may present with other complaints and these will be dealt with accordingly.

The new standards will mean a quicker response to a crisis and a better level of care overall. We want to make sure that everyone living with sickle cell is getting a high level of care; so if this is not your experience then please get in touch with our helpline.

You can find more information on the new standards on the NHS Website.



# Tribute to Emmanuel Christian Amuta (29 August 2003 – 19 September 2017)



The Sickle Cell Society were deeply saddened to hear of Emmanuel's passing on 19th September as he was a very special boy to us not least because he stole the show at our AGM in 2016 and at the launch of our South London Project this February 2017 by reciting his poem 'A Beautiful Cell' which inspired so many others living with sickle cell disease. I first met Emmanuel about six years ago when he and his mum Umu were introduced to me at one of our AGM meetings in Victoria. At that time, I was the Society's Regional Care Advisor for South London and they fell into my patch of service users as they were members of the Greenwich Sickle Cell Support Group. Emmanuel created a lasting impression on me that day not only because he was the cutest youngster I had seen for a while but because even at 8 or so years old his caring nature came through when I mentioned to him that he was eligible to go on the Society's annual Children's Holiday. Whilst other boys of his age would have jumped at the chance and not looked back Emmanuel said to me "I can't leave my sister" (as Nkem does not have sickle cell she was not eligible to go along on the holiday). It is very difficult to write a tribute for someone taken away at such a young age so I decided to list some of his characteristics and say from my perspective why I think they are warranted. Quite by coincidence most of these characteristics start with the letter 'C'!

**Cute** – Well we all knew what a handsome youngster he was and you only have to look at the beautiful and photogenic pictures of him to confirm or look at his beautiful mum.

**Caring** – He cared about others especially his younger sister hence he would not go on our one week Children's Holiday without her.

**Courageous** – Emmanuel was living with the debilitating condition of sickle cell and bore it with much courage very often not wanting to make a fuss when he was ill.

**Clever** – Emmanuel might have only been a youngster but he was much older than his years when you conversed with him. I was in a focus group with him at one of our AGM's discussing patient experiences of sickle cell and I can honestly say he contributed much more than some adults in the group! This is why he was always the first youngster I thought about if we needed to recruit young people to a project and he was my first choice for a 'Terrific Teens Digital Video Workshop' reported on in this newsletter.

**Confident** – At our AGM he stood in front of 150 or so people and recited his poem 'A Beautiful Cell'. He wasn't nervous and confidently mentioned that it was an old poem but he had since improved on it. One poignant line read: "To me sickle cell is a gift if you have it you shouldn't be ashamed of it" thus trying to remove the stigma so prevalent with the condition.

**Charming** – Even at such a tender age Emmanuel was a charming young man. When I first visited him in hospital this last time even as he lay in bed gravely ill he whispered "my second best lady in the world".

The last characteristic is one that describes his dress style even for one so young. I couldn't find a word beginning with 'C' but got one close enough – 'Dapper'! At our South London launch in February he was by far the best dressed man in the house. He and I took this beautiful picture together which I will always cherish.

On behalf of the Sickle Cell Society our deepest sympathy goes to Umu, Chris, Nkem and all the family. The Society will continue to show you how special he was to us. May he Rest in Peace.

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

# Children's Holiday



From the 19th to 26th August the Sickle Cell Society took thirty children with sickle cell on an amazing adventure holiday to PGL Liddington. Alongside learning about their condition and making friends 'just like them', the children experienced activities such as climbing, zip line, quad biking and fencing, as well as evening activities such as a talent show and disco. The children, who were split into three teams (Lions, Tigers and Bears) based on age group, slept in shared dormitory rooms with bunk beds to give a real summer camp feel to their experience. The children told us that they had an amazing time and had learnt lots about sickle cell, bravery, independence and confidence. Their favourite parts were the giant swing, making friends and cabin chat at the end of the day, especially the brilliance beads!



Parents were delighted with their child's experience of the holiday too and have cited increases in confidence, ability to deal with their sickle cell and independence – a success! After the holiday one of the parents told us: "My daughter had a wonderful time and it has helped her to come into herself and giving her confidence. Also it help her to know her sickle cell won't stop her achieving what she wants to be in life."

The holiday was supported by a brilliant team of sixteen volunteers who pulled together to make sure that all the campers were safe, well and happy all week. One of our volunteers told us: "Spending a week with children with Sickle Cell has been the most amazing experience, the sheer strength and determination in them was just phenomenal. A truly heart-warming experience."



This year's Children's Holiday will be at the Pioneer Centre near Kidderminster from Saturday 18th August to Wednesday 22nd August 2018. All children aged 8-15 years old with Sickle Cell are welcome to apply to attend. We are also looking for volunteers who would like to spend the week helping the children have a marvelous time. You can find more information on our website and on our social media pages. Places are limited, so make sure to get your application in now!

A poster for the Children's Holiday 2018. The background is blue with white stars. At the top is the Sickle Cell Society logo. The main text reads "CHILDREN'S HOLIDAY 2018" in large yellow letters, followed by "FOR 8-16 YEAR OLDS LIVING WITH SICKLE CELL" in smaller white letters. Below this are three circular images showing children at various activities. The dates "18TH TO 22ND AUGUST" and location "PIONEER CENTRE (SHROPSHIRE)" are listed. A yellow box contains the invitation text: "We would like to invite YOU to the Sickle Cell Society's annual children's holiday. Get ready to enjoy a FREE fun-packed week full of activities such as zipline, archery and indoor caving, all whilst making lifelong friends and learning more about managing your condition. Doctors and Nurses will be on hand for any medical care that you may need during the week and all accommodation, food, activities and transport from Central London is provided. It's time for an adventure!" At the bottom, it says "FOR MORE INFORMATION: TINYURL.COM/CHILDRENS-HOLIDAY-2018 02089 617795" and a yellow starburst says "FREE!".

# Children's Activities

Our Children's Activities programme funded by BBC Children in Need is now one year old! Over the past 12 months over 110 children who are affected by sickle cell have enjoyed a whole host of free exciting and educational activities in London. Highlights have included a day trip to Thorpe Park, a DJ workshop, a trip to see Wicked, climbing, trampolining and escaping from a ClueQuest escape room.

We have loved seeing the children have so many adventures together and make friends with others who are affected by sickle cell. One parent told us: "They have been able to try new things and building their self-esteem and confidence, knowing they can do things like other kids. They love going out with kids with same condition to have fun!"

Does your child have sickle cell? Would they like to take part in a free activity or two in London? Please e-mail [info@sicklecellsociety.org](mailto:info@sicklecellsociety.org) for more information or check us out on social media.



## Tropical Sun marks 21st Anniversary with Sickle Cell Society partnership and donation



At the Sickle Cell Society, we rely on donations and fundraising to support our work. That's why we were so delighted to be contacted by Tropical Sun and to hear that they wanted to support us. Tropical Sun is celebrating its 21st birthday by investing £21,000 towards community projects in Jamaica and the UK and we were one of those chosen community projects.

At a presentation event at our headquarters, we were overjoyed to officially announce that Tropical Sun were donating £2,000, plus £1,000 worth of Tropical Sun products such as coconut oils, coconut water and teas that we have distributed to our service users to aid them with managing their health.

The representatives from Tropical Sun Foods were also extremely interested in our involvement with the Breaking Down Barriers project, and they've been working hard on a number of community projects including renovating two schools local to their factory in Jamaica, to enable the children of their factory employees to benefit from a safe and functional environment to study.

Our Chief Executive, John James, said: "The Sickle Cell Society are very grateful for the support and donation from Tropical Sun. Sickle cell disorder mostly, but not exclusively, affects people from African and Caribbean backgrounds, so it is good to see that Tropical Sun, a company with its roots in the Caribbean, is supporting these communities."



## The Sickle Cell Society and Breaking Down Barriers



The Sickle Cell Society has partnered with the Breaking Down Barriers funded by the Sylvia Adams Trust. In September 2016 we received a £5000 grant as members of The Breaking Down Barriers Project in order to help us further support our service users with French and Portuguese resources.

We came to this decision after cross referencing the most widely spoken languages in the UK with ethnic groups that experience a higher incidence of SCD and found that we needed to prioritise translation into French and Portuguese.

The Breaking Down Barriers Project's is managed by Alström Syndrome UK. As a collective we aim to meet regularly to discuss development and updates in order to gain greater understanding of the impact of living with a genetic condition, in order to improve the standards of our service users and support by our service users.

For further information you can contact Linda at [linda.chic@sicklecellsociety.org](mailto:linda.chic@sicklecellsociety.org)

## Celebrating Black History Month 2017

2017 was the 30th anniversary of the UK's Black History Month – celebrated every October to recognise Black history, achievement and contribution. October is usually one of our busiest months at the Society as we get asked to give sickle cell awareness talks at many 'Black History Month' events around the country, some of which also raise funds on our behalf. For many years I have added a historic slant to my presentations on sickle cell (particularly in October!) to include information on Dr Africanus Horton of Sierra Leone who in 1859 was the first African graduate of the University of Edinburgh and who should be credited for first describing the disease that subsequently became known in the West as 'sickle cell'. In his book 'The diseases of Tropical Climates and their Treatment' published in 1874, Horton described all the symptoms of a disease that were the hallmark of sickle cell including the persistent abnormality of blood and painful episodes associated with fever and increased frequency during the rainy season. Last October I gave two such presentations at events organised by the Home Office Network (for Black and Minority Ethnic staff) and

the British Bone Marrow Registry in Bristol which is part of NHS Blood and Transplant. The presentations were entitled 'Sickle Cell and the Africanus Horton Story' and for the talk in Bristol which was to staff from NHS Blood and Transplant I included a second presentation entitled 'Showcasing Dr Charles Drew: the African who started the world's first large scale blood bank'. As usual both presentations generated a lot of interesting questions and discussion not only on sickle cell but also on the related medical contributions from the likes of Horton and Drew which in most cases people know little about!



Iyamide with Home Office Network event organiser Fasil Onimole as she takes questions from the floor

By Iyamide Thomas –NHS Engagement Lead

# Fundraising Spotlight



Well done to Sam Alexander and Paula Wessley who ran 10K and raised an amazing £595 for us.



A huge thank you to Greater Heights for raising a wonderful £800 for us at their charitable ball in June.



A big thank you to Nia Allen-Cooper for completing The Colour Run London 2017 and raising £165.34.



Thank you so much  
Digital Wealth Society

A big thank you to the Digital Wealth Society for raising a phenomenal £26,142 for us. What superstars!



A huge thank you to Naomi White who raised over £2000 by completing an incredible challenge of swimming the English Channel in a three-person relay in 11 hours and 59 minutes.



Thank you to Fasil who raised over £500 for the society by completing a triathlon.



Thank you and well done to James Brown who completed the Darlington 10K Run for us.



A big thank you to Nia Allen-Cooper for completing The Colour Run London 2017 and raising £165.34.



A big thank you to the National Bank of Kuwait for raising £215 for us through their delicious food.





A massive thank you to the Vin Club for raising £8800 for us through their charity ball and walk



A huge thank you South Thames College for running up 40 floors to complete the Gherkin Challenge to promote awareness of sickle cell.



A huge thank you to Patricia Johnson for organising a Black History Month Event at Harrow Leisure Centre which raised £115.00.



A great big thank you to dedicated fundraiser Lucreta La Pierre for raising awareness and raising £305 at the Comedy Link Up show at the Broadway Theatre Catford. A huge thank you to the generous audience as well.



A big thank you to COGIC for donating money to support us at their Black History Month celebration



A big thank you to Gabriella Joseph at Bowland College, Lancaster University for organising a cake sale and raising £72.60 for us.



A big thank you to the Catenian Brothers of Hastings 66 Circle, Sussex Province for donating £750.

# RegMedNet Interview with John James

In August, John James was interviewed for RegMedNet, a networking site where users can share their knowledge and insights on regenerative medicine. In the interview John discussed the high prevalence of sickle cell disorder in the UK and the lack of options available to treat it. Also interviewed was Dr Mohammed Asmal, the vice president of Clinical Development at bluebird bio. Together they discussed the new treatments which are being worked on, including gene therapy. The overall feeling of the interview was that of hope for the future. The new treatments being worked on could provide a much wider array of options for people living with sickle cell, however there is still a long way to go.

You can read the full interview at the [www.regmednet.com](http://www.regmednet.com)

# Volunteer Voice

Living with sickle cell has taught me to stay strong and be positive about certain situations. I can't help how I was brought into the world but I can control what happens there after. Not many people recognise what sickle cell is and how it can easily influence your everyday life but volunteering for the Sickle Cell Society, I got to see how they provide for people that are living with sickle cell by raising awareness, giving support or information and also letting their [people with sickle cell] voices be heard.



# Mentoring Update



Since launching in August our mentors, June, Whitney and Michael, have been busy meeting some of Hackney & the City's inspiring young mentees. They have supported and encouraged mentees on a wide range of matters and have witnessed the determination and ambition shown by many mentees in tackling sickle cell related challenges.

In the New Year, the mentors are keen to see how they can help more young people through mentoring. In particular, they want to help young people living with sickle cell to manage the condition proactively and have the ability to live a wholesome and independent life.

They have delivered talks and presentations to raise awareness of both sickle cell and the new mentoring programme. They have also met with the clinical teams at the Royal London Hospital and the Hoxton Surgery to learn more about the services available for sickle cell patients within the borough. As board secretary for the Solace Support Group, a support group serving the sickle cell and thalassaemia community in Hackney, June has been working hard to encourage young members to make the most out of the mentoring programme.

Whitney has thoroughly enjoyed helping to "make a long-lasting positive impact" and Michael has expressed how rewarding it has been to "witness a young mentee find his own solution to a challenge he was facing by simply being there and listening." Mentees Gloria and Stefan have also found the experience truly beneficial, mentioning that it has been a "good growing experience learning what sickle cell is and how to deal with it" and that mentoring provides "a listening ear to voice concerns and worries." Sam, also a mentee, confirmed that mentoring has helped him to "focus on the things that doctors don't cover." Parent feedback highlights how mentoring "has made such a difference in my daughter's life. She is so confident and speaks up now."

# Keeping Croydon Warm This Winter

Annie McDonald the secretary of Croydon Sickle Cell and Thalassaemia Support Group got a pleasant surprise recently when a lady called Elizabeth who is the South London Coordinator for Project Linus UK phoned the office. She asked whether we would be interested in quilted blankets for the children in our group. Project Linus UK is a volunteer organisation that aims to provide a sense of security and comfort to sick babies, children and teenagers through the provision of new home-made patchwork quilts and knitted/crocheted blankets and give volunteers across the UK the opportunity to contribute to their local community. Elizabeth said that each year they donate to various causes; weren't we lucky that this year they chose us! When we collected the blankets they were very beautiful and well-made and guaranteed to keep the children warm. A huge thank you to Project Linus UK!



Members and trustees of Croydon Support Group show off some of the blankets



**SICKLE CELL SOCIETY**

## MENTORING SCHEME

**For 10-24 year olds living with sickle cell in Hackney and City**

Do you know a young person who could benefit from support and advice in one to one mentoring sessions? We are actively seeking referrals from GPs, social workers, teachers, carers and family members to our FREE mentoring scheme. The service is led by peer mentors (June, Whitney and Michael), all of whom have sickle cell themselves.

**TO REFER A YOUNG PERSON:**  
[MENTORS@SICKLECELLSOCIETY.ORG](mailto:MENTORS@SICKLECELLSOCIETY.ORG)  
07377 170152



# North West Sickle Cell Patient Conference – Manchester

In November we partnered with Central Manchester Foundation Trust to run the North West Sickle Cell Patient Conference. The event took place in Citylabs in Manchester and comprised of a range of talks and discussions around the most pressing issues for sickle cell patients.

The event was hosted by Dr Kate Ryan, a leading expert in haemoglobinopathy and we had talks from other healthcare professionals on a range of topics. Dr Rachel Kesse-Adu started things off by giving a detailed presentation on the various research and clinical trials that are going on. This was followed by John James discussing the importance of those clinical trials and why people should get involved. After lunch Rebecca Challinor talked to us about the importance of social work in helping people with sickle cell. Anthony Mason of Sickle Cell Care Manchester followed this by stating the importance of community support which was re-enforced by Chantelle Hemmings' talk on why hospital care and community support must work together.

Overall, the conference was a huge success. There was plenty of time for Q and A and we got to hear the concerns and thoughts of many health professionals and most importantly, sickle cell patients. One attendee said "this was the best conference I have attended in Manchester and it was great to have the sickle cell society present." Another said that "we patients need to attend things like this to know what is available to us as patients."

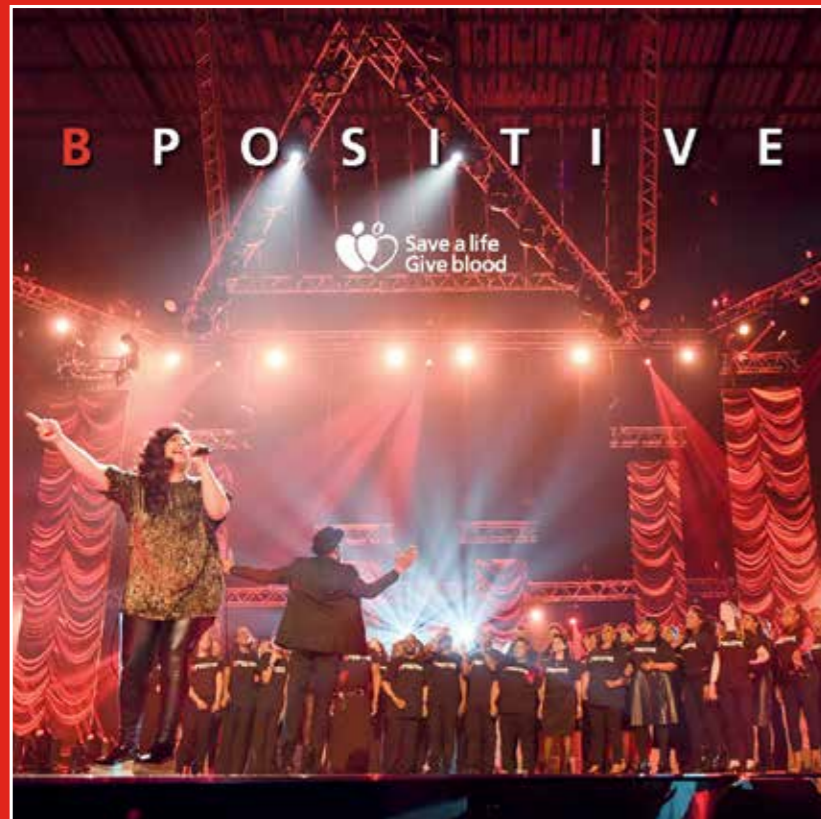
We are planning to run similar events in different places across the UK so keep an eye on our social media channels and website to see when they will be.

# Hackney Sickle Cell Annual Patient Conference

In October we had the Hackney Sickle Cell Annual Patient Conference. The conference was a full day of talks on the most pressing issues as well as lots of opportunities to get feedback and questions from patients. There were speakers discussing everything from clinical trials and new treatments to sickle cell in schools and our Hackney Mentoring project. We were also joined by special guest Diane Abbott MP.



# B-Positive Choir



NHS Blood and Transplant joined forces for the second year running to promote blood donation and to highlight how donating can save lives. Together they have created the B-Positive Choir. The choir brings together people who live with sickle cell, their helpers, friends and families.

With a spectacular performance at the MOBO Awards 2017, the choir are on a mission to get new donors and to highlight the ongoing need to give blood to help patients, like people with sickle cell.

In December they released their first single 'Rise Up': their rendition of the hugely inspiring Andra Day original. With lead vocals by gospel sensation, Lurine Cato, the release aims to encourage more people to 'Rise Up' and be counted as blood donors, as well as raise vital funds to help support the life changing work of NHS sickle cell wards.

You can find 'Rise Up' on iTunes, YouTube and other music streaming services.

# See The Dream

A group of teenagers and young people attended a motivational workshop entitled SEE THE DREAM by the well-known motivational and world-class speaking coach, Alex Gordon from Master Your Message. The workshop was held at the Sickle Cell South London Link (SCSLL) located in Longfield Hall, SE5 on the 25th August 2017.

The workshop encouraged the teenagers and young people to explore their dreams and strive to achieve their goals, making their dreams come true. Kreme who attended the workshop said that "the workshop was fun and very engaging. It opened my eyes as I knew what I wanted to do but never thought about how I was going to make it happen, you know, step by step. Alex really helped me see that it is possible to achieve anything."

Each person at the workshop received a free signed copy of Alex's publication, What Is Your Dream together with a 'Think 100x Big' workbook.



# Sickle Cell South London Link

Sickle Cell South London Link (SCSLL), held its first employment themed workshop at Canada Water's Culture Space in South London. This was the first of many workshops that will be held over the three-year period in which the project is funded by the Big Lottery Fund.

SCSLL recognizes there are many people with sickle cell who have a lot to contribute and are achieving amazing things and that's why we are encouraging patients to meet, teach and learn via a series of workshops and support groups.

The first speaker gave a heart-warming and motivational account on her life; she shared the triumphs and tribulations of balancing work and health. The take-a-way was to never give up and with a little help and a lot of support it is possible for people living with sickle cell to not just provide but to thrive. Our speaker's end note was to create opportunities for yourself and to network.

Welfare Support advisor Daniel Nyakutsey then informed participants of an alternative way to view the use of benefits such as PIP to assist and enhance their work life. PIP is invaluable

because it's non-means tested meaning you can work and claim. Cold rainy mornings outside waiting for the bus now becomes a warm cosy cab ride. Use a mobility car to arrive at work pain free and have a more productive day. PIP can give a little more security and a lot of peace of mind when taking unpaid sick days.

People with sickle cell are sometimes known on social media as Sickle Cell Warriors. As a Sickle Cell Warrior, I fully understand the difficulties related to not just getting a job, but keeping it. Being fired or penalized due to difficulties related to any disability is illegal, therefore no one needs to suffer in silence. I say "FIGHT BACK!" We are warriors that battle sickle cell every day. Winning is the greatest feeling and what we do best.

One person said that the workshops were "A very good initiative that needs to be continued to enable awareness on a large scale" and another said "it's great to hear the perspectives of others and gain strength from their experiences."

You can contact The Sickle Cell South London Link on 0203 8799 535/ 0208 961 7795. Alternatively check out our website: [www.sicklecellsociety.org](http://www.sicklecellsociety.org) for support, information and of course to volunteer.

By Aimy Agginie

# Thanksgiving Service



2017 saw the Sickle Cell Society's Annual Service of Thanksgiving and Remembrance being hosted by Reverend Canon Stephen Coulson of St Marks Church Kennington in Lambeth, South London - for the third time! The service held on the 2nd July was also a memorial gathering for the Society's dear colleague Comfort Ndivo who passed away on 27th October 2016. Our

distinguished guest Councillor Marcia Cameron, Mayor of Lambeth joined Comfort's family, Society trustees, staff, friends, and supporters such as Dr Lola Oni (Service director, Brent Sickle Cell and Thalassaemia Centre), Dr Asaah Nkohkwo (the Society's past Chief Executive Officer) and Dr Maria Berghs (Academic Fellow De Montfort University who had worked on a joint project with Comfort and I).

The service theme was 'caring for sickle cell' and we acknowledged all those who in one way or the other care for people with sickle cell: from parents of affected children to other extended family members, as well as people in the community such as health professionals, voluntary organisations and support groups. Special tribute was paid to Comfort's very caring spirit not only with her work at the Society but also with her Cameroonian community who fondly called her 'Ma Comfort'. As Comfort loved to dance, the congregation obliged my request to get up and dance to a gospel song I know she would have loved! Our guest preacher the Rev. Hannah Neale gave an inspirational address very pertinent to the day's theme whilst Jo-jo Philips received a standing ovation with her solo rendition of the Etta James classic 'At Last'. After what many described as an enjoyable service there was the usual networking and refreshments before many began their easy journeys home from Oval underground station conveniently located across the road!

# Patient Education and Training Lead

We will be running workshops in London, Manchester, South Yorkshire and the Midlands to support and empower young adults aged 18 to 25 living with sickle cell. Our new education and training project is being funded by Bupa UK Foundation as part of its the Healthy Futures funding programme.

The workshops will primarily target young people aged 18-25 with sickle cell disorder and their families. They will cover practical topics, from managing sickle cell independently to communicating one's condition in education and employment. Alongside the workshops there will also be online resources developed for those that are unable to physically attend. The sessions will also empower those living with sickle cell to explore their options and support available in relation to pursuing employment and entrepreneurship, travelling or seeking financial aid to enable them to reach their full social and economic potential.

To run this project, we have appointed Siann Millanaise as the Patient Education and Training Lead. Siann will focus on empowering people living with sickle cell through the educational workshops, creative activities, and through advice and information. She will also work on providing a supported and safe place for people to share, connect and have their voice heard.

Siann Millanaise said "I am very excited to be taking on this role and look forward to enabling individuals within the Sickle Cell community. I hope to engage and empower those living with sickle cell to fulfil their aspirations and enhance their quality of life."

Tina Gwynne-Evans, Head of the Bupa UK Foundation, said: "The Bupa UK Foundation's Healthy Futures funding programme aims to empower young adults living with health challenges, so we are people pleased to be supporting the Sickle Cell Society to deliver workshops and advice to help young adults living with sickle cell to live life to the full."

If you would like to get involved with the project or wish to find out more, please email [Siann.Millanaise@sicklecellsociety.org](mailto:Siann.Millanaise@sicklecellsociety.org)

We are also looking for Regional Support Leads in each area to help promote and assist the education and training. Visit our website to find out more about this paid job role: [www.sicklecellsociety.org/regional-support-lead/](http://www.sicklecellsociety.org/regional-support-lead/)



# The Dr. Adebayo Olujohungbe Award

Do you know a health professional (e.g. occupational therapist, psychologist, nurse, doctor, and receptionist) or adult sickle cell team who has made significant improvements or provided high quality care for adults with sickle cell disorder?

If so, then please consider nominating them for the Dr Adebayo Olujohungbe Award.

## What is the 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 Adults Standards of Care for Sickle Cell. His mission was to ensure that all adult patients with Sickle Cell received high quality of care from health professionals.

## What will the winner of the award receive?

We have two one off awards of £3500 for the health professional or health team to use to improve care for adults with sickle cell.

If you are lucky enough to nominate the winner, you will receive a £100 gift voucher.

## How to nominate?

To nominate a person or team please visit our website: [www.sicklecellsociety.org/award/](http://www.sicklecellsociety.org/award/)

The deadline is 31st March and winners of the award will be announced at the Sickle Cell Society AGM in 2018.





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](http://www.sicklecellsociety.org/become-a-member)

[www.sicklecellsociety.org/donate](http://www.sicklecellsociety.org/donate)

Charity number: 104 6631

Sickle Cell Society, 54 Station Road, London NW10 4UA

Telephone: 02089617795

[www.sicklecellsociety.org](http://www.sicklecellsociety.org)