




Sickle Cell Society Newsletter Winter 2016



**SICKLE
CELL
SOCIETY**



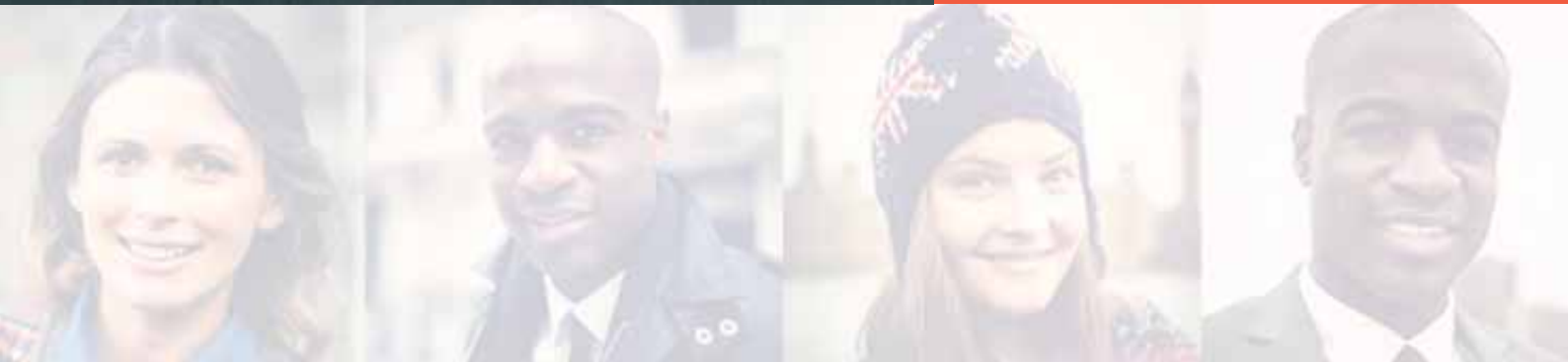
The Children's Holiday

**Annual General Meeting
and Education Day**

Goodbye, Comfort Ndive

**Mixed Blessings from a
Cambridge Union**

...more inside!



A community service for Individuals with SCD
in Lambeth, Lewisham & Southwark

SICKLE CELL South London Link



CHILDREN / TEENAGERS / ADULTS

Free Activities & Social Events

Support Groups

Information & Education Workshops

for those with Sickle Cell Disorders and their families

If you would like to find out more about our project activities register using the link below:

sicklecellsociety.org/sickle-cell-south-london-link-service/

If you are interested in volunteering at a project activity email us at:

info@sicklecellsociety.org



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A welcome from the Chair

Our Winter edition of the Sickle Cell Society newsletter is bigger than ever. Catch up with the latest news from our Annual General Meeting, and our 2016 Children's Holiday. It's all go with the local groups, from Cardiff all the way up to Glasgow, there's been loads going on. Sadly, not all of our news is good news: this year, our community has been hit by some devastating losses. We celebrate the lives of those who have passed, and remember how their lives touched ours.

We hope our newsletter will warm your heart through the cold winter months... and please remember to stay healthy and warm yourself!

Sickle Cell Society annual general meeting and education day

The Sickle Cell Society's Annual General Meeting took place on 23rd July, right in the heart of Sickle Cell Awareness Month. As always, it was fully-booked and well-attended, a lively mix of people living with sickle cell, families affected by sickle cell, healthcare professionals and researchers. The Grand Connaught Rooms was full with people who care.



The financial year 2015/16 had been another good one for the Society, with a small surplus for a second year in a row. We had achievements to celebrate, as well as a year to look forward to. The morning session ended on a high, as 11 year old Emmanuel read his poem “A Beautiful Cell,” about his life with sickle cell.

The Education Day aspect focused on research conducted last year, which we reported in the last issue of the Newsletter: the Patient Reported Experience Measure (PREM). This was the first nationwide survey of patient experience in sickle cell, with over 700 patients and carers participating. The survey found that a lack of awareness of sickle cell among healthcare professionals led to negative experiences among patients. After a presentation of the findings from researchers from our partners, the Picker Institute and



North West London CLAHRC, who conducted the research, it was time to work out what should be done!

A table-based workshop encouraged discussion of the findings of the PREM survey and how best to address the issues it raised. The discussions were perceived to be very constructive, bringing together people affected by sickle cell, and those who they felt needed to be more aware. Throughout the discussion, education of patients, carers and clinicians alike was a constant theme, considered highly necessary for all—as well as training and education for others, such as teachers and GPs. The Society has taken these ideas into consideration, and we will do what we can to raise awareness!

The day ended with a raffle, with fabulous prizes including haircare products, jewellery, drinks and clothing, which raised £179 for the Society.



To read more about the findings of the PREM survey, or to watch video of Emmanuel’s poem, visit our website: www.sicklecellsociety.org

CHILDREN’S HOLIDAY

One of our favourite times of the year is August, because August means the Children’s Holiday! This year, we took 24 children living with sickle cell to what’s becoming our home-from-home: King’s Park. The purpose of the holiday, as always, was to give the children and carers respite, an opportunity to meet other young people with sickle cell, and to teach them how better to manage their condition.

Throughout the week-long break, the children enjoyed a mix of educational workshops, activities and outings. The educational workshops were led by nurses, teaching the children about understanding and managing their sickle cell. The indoor activities included arts and crafts such as mug-designing, fabric painting and mask-making, as well as sports and board games. The green areas around Kings Park were ideal for ball games, skipping and hanging out with new friends.

There were two outings for the children, which many of them considered to be a highlight. A whole day was spent at the theme park Drayton Manor, so the kids could enjoy the rides and adventures. The next day, an afternoon was spent at Laser Zone where the children played laser tag. As always, the delightful week ended with a talent show where the kids showed off their skills to their new friends, and a disco!

Kye Gbangbola MBA FCIQB CIHM EurBE GDA MIEMA CEnv GASCO LCSAP
Chairman, Sickle Cell Society



SAVE THE DATE! The next Annual General Meeting will be held on Saturday 22nd July 2017. The venue is not yet confirmed, but we’ll let you know as soon as possible.



Brent Sickle Cell Advice and Support Service: still standing

If you live in the London Borough of Brent, you may have been concerned by the front-page news in the Brent and Kilburn Times that the Brent Sickle Cell Advice and Support Service (BSCASS) was imminently closing.

Fortunately, the BSCASS has been saved due to pressure from the Sickle Cell Society, local patient groups, and the Brent community. It was agreed at the Governing Body Meeting of Brent Clinical Commissioning Group (CCG) on September 7th that BSCASS will continue to provide its information, advice and support services to Brent residents living with sickle cell disorders until a viable alternative service is proposed.

Responding to the news that the Brent Sickle Cell Advice and Support Service will not be imminently closing, John James, CEO of the Sickle Cell Society said: *"We are pleased to hear that Brent CCG has changed its mind in immediately decommissioning the Brent Sickle Cell Advice and Support Service. The service has been helping people living with sickle cell in the borough, and we are delighted to be able to continue with this work for the foreseeable future."*

The Sickle Cell Society are happy to work with Brent CCG in developing a community service for people affected by sickle cell, and we will engage throughout the process. We are grateful for the support given to us throughout these uncertain times from patients, healthcare professionals, politicians and Brent Patient Voice."

The Sickle Cell Society continues to engage with the community and the CCG to put forward the specific concerns and needs. The BSCASS remains open. If you are a Brent resident living with sickle cell disease, you are eligible for the support provided.

Visit our website for further details of how to refer: www.sicklecellsociety.org

A SPOOKTACULAR bowling trip



The Sickle Cell Society's new Children's Activities Programme, funded by BBC Children In Need, took children on their first activity on 28th October. Children affected by sickle cell went bowling, with volunteer carers, at Royale Leisure Park in Park Royal. Since it was Halloween, there were some fabulous scary costumes!



Sickle Cell and Thalassemia in Wales: stories from past, present and future.



Sickle cell is an important part of Black History Month. On 22nd October, Friends of Cardiff Sickle Cell and Thalassemia held a celebration event titled Sickle Cell and Thalassemia in Wales: Stories from Past, Present and Future. The day consisted of a series of talks, providing a comprehensive

overview of the story so far, and a look at where we would all like things to be. Sickle Cell Society founder and patron, Professor Elizabeth Anionwu, presented her reflections on the history; John James, CEO, gave an overview of the current situation, while Elaine Miller from the UK Thalassemia



Society talked about the state of affairs for thalassaemia. Annette Blackmore, a Cardiff and Vale specialist nurse, led a discussion on the future. Signed copies of Professor Anionwu's memoir, *Mixed Blessings From A Cambridge Union* were available.

The day's speaker Faye Walker, leader of Friends of Cardiff Sickle Cell and Thalassemia, speaks.

Glasgow's children and family event

The Scottish Society for Sickle Cell and Thalassemia held an event for children and families affected by sickle cell and thalassaemia in October. The families came together at Glasgow Science Centre to meet, network and have fun.



Society patrons celebrate historic Mary Seacole statue

On 30th June, a statue of nurse Mary Seacole, who cared for soldiers wounded in the 19th century Crimean war, was unveiled. This statue is the first historic memorial of a black woman in the UK.

Sickle Cell Society patron Professor Elizabeth Anionwu has been an active participant in the campaign for Mary Seacole to be honoured for many years, and was at the unveiling.

Also present were Baroness Benjamin and Baron Boateng, both long-serving patrons of the Sickle Cell Society, and the Society's CEO, John James. Baroness Benjamin presided over the unveiling ceremony.

Mary Seacole was Jamaican-born and studied and travelled widely. In 1854 she travelled to England and asked to be an army nurse in Crimea. She was refused, but Mary Seacole was a remarkable woman and didn't give up--she went anyway. She was known as Mother Seacole. Mary Seacole made her own way as a black woman and saved many lives.

Professor Elizabeth Anionwu said of the statue: *"For somebody like myself, a nurse of mixed heritage - Mary was Jamaican-Scottish, I'm Nigerian-Irish heritage - there's a link there. I have an eight-year-old granddaughter, and at last youngsters will be able to see a beautiful monument that they can identify with."*



Baroness Benjamin and Professor Anionwu stand in the centre of the unveiling of Mary Seacole's statue.



See the statue for yourself at St Thomas's Hospital, London

Sickle cell disease research and development

We are delighted to inform you that the National Institute for Health Research (NIHR) has launched a call for research proposals as part of its Health Technology Assessment Programme. The research proposals seek to address the question 'is haematopoietic stem cell transplantation in adults with severe sickle cell disease cost effective and does it improve quality of life?' The society, who have lobbied for this with NHS clinicians, welcomes this initiative. We will keep you informed of progress as things develop.

Introducing the South Yorkshire sickle cell organisation

The former Sheffield Sickle Cell and Thalassaemia Foundation (SSCATF) had been operating in Sheffield for many years but due to the withdrawal of funding by the Sheffield City Council they had to fold the company in September 2014. SSCAT Management Committee members have been working in the background for the last 18 months because they believe it is important Sickle Cell clients have community based support as well as clinical support, and decided to open a new charity called South Yorkshire Sickle Cell Organisation (SYSCO). South Yorkshire Sickle Cell Organisation (SYSCO) launched the company on Tuesday 25th October 2016 in Sheffield.



The event was well attended with attendance from The Lord Mayor as well as speakers Mr. John James (Chief Executive Sickle Cell Society), Professor Simon Dyson (De Montfort University), Anthony Mason (Sickle Cell Care Manchester) and representatives from the Sheffield Children's NHS Trust Dr. Jenny Welch (Consultant Haematologist), Louise George (Haematology Nurse and Specialist and Sheila Daley (Specialist Nurse Counsellor for Haemoglobinopathy). South Yorkshire Sickle Cell Organisation (SYSCO) aim to continue to raise awareness of the disorder and our long term goal is to employ workers to support people living with sickle cell in South Yorkshire.



IN LOVING MEMORY

Comfort Ndiva

We are sad to inform you that Comfort Ndiva has passed away on 27 October 2016 following a short illness. Comfort worked with the Society for over a decade on many of our projects, starting with the Hackney Sickle Link project, progressing to Lambeth Sickle Link, the Regional Care Adviser project and the Brent Sickle Cell Advice and Support Service. She was well-known in the sickle cell community in London and beyond, providing advice, information and support on behalf of the Society throughout the city. Comfort took an active role in organising our annual Children's Holiday, which provides respite and education to children with sickle cell. Comfort Ndiva was a dedicated and passionate advocate for the sickle cell community, and she will be truly missed. May her soul rest in peace.

For a full tribute to Comfort detailing the years of dedicated service she gave to the sickle cell community, please visit our website www.sicklecellsociety.org



Comfort Ndiva



Sally Ann Ephson

Sally Ann Ephson

Councillor Sally Ann Ephson passed away in September. Cllr Ephson was a committed friend of the Sickle Cell Society who served two terms on our Board of Trustees. She was a passionate advocate for the sickle cell community, using her platform and position to speak on these issues, and was active in her local support group, too. She was a frequent face at our Annual General Meeting, a true and much-loved friend.

Her vocal advocacy for the sickle cell cause had an impact high up, bringing us and our issues to the attention of the Mayor of London himself. Speaking of the passing of Cllr Ephson, Sadiq Khan, said: *"Sally-Ann also served on the board of the Sickle Cell Society, and was a strong advocate for both improved access to and better quality of care for those with the disease. I will remember Sally-Ann fondly as a dear friend, determined campaigner and, above all, as someone who never stopped smiling. Rest in peace, Sally-Ann."*

Dr Allison Streetly OBE BA MB BChir MSC FFPH, National Programme Director NHS Sickle Cell Screening Programme (2001-2013) says: "As well as her contributions to the Sickle Cell Society Sally Ann also made a real contribution to the development of national networks of care for sickle cell disease through her lobbying to get M&S to fund research including the FAIR SHARES report, outlining how services should work across health and care."

I first met Sally Ann nearly 20 years ago in early 1997 at the Launch of the "Fair Share for London" report at the Brixton Ritz which Trevor Phillips attended. Sally Ann was key to our team getting the funding to undertake the work to produce this report which is still widely referred to. The "Fair Shares" report was important in informing the plans for national specialised commissioning of specialised services for sickle cell disease.



Kirsty Sekiwu



Councillor Tayo Oladapo

After that I continued to meet with Sally Ann for the duration of the time I set up and ran the national programme a few years later.

She was a fantastic supporter of the Screening Programme and its development. I met her at many events in Westminster and elsewhere where her energy, smile and positivity (as well as glamour) helped ensure that patient views were always to the fore in discussions and plans - her willingness to speak about her condition something that was often resisted by those with sickle cell disease back then but so important for raising the profile. Thank-you Sally Ann your legacy lives on."

Sally Ann Ephson will be missed by all at the Society. May her soul rest in peace.

Kirsty Sekiwu

Kirsty Sekiwu passed away in March, at just 11 years old, following complications from a bone marrow transplant. In June, her school held a school service, celebrating Kirsty's life. The whole of St John's and St Clement's Primary attended this moving service. Kirsty's favourite colour was purple, so the children wore purple and released purple balloons. Kirsty was bubbly and sassy, and a friend of the Society: in 2015, she attended the Children's Holiday. She is remembered fondly by the volunteer carers who attended the holiday.

After the service, the school presented the Society with money they had raised in Kirsty's memory. We are hugely grateful to St John's and St Clement's, and to Kirsty's for the lives she touched in her own short life.

Councillor Tayo Oladapo

Tayo was born in London and spent his childhood in Nigeria. He returned to the UK aged 20 and studied Journalism at Kingston University where he got a very good Honours degree, almost first class, his mother has told

us. Although aspiring to be a journalist and writing a novel, Tayo followed his other interests - immigration issues and politics. In 2008 as a Labour Party member he worked with Kilburn Labour team to promote engagement and inclusiveness in South Kilburn. He co-led a project which developed the skills and social media techniques of the Obama presidential election campaign.

In 2009 he was selected as a candidate for the local council and a year later he was elected. Popular with local groups and especially young people and the neighbourhood police panel, Tayo learned fast and soon earned a reputation for being effective, highly principled and a passionate, rather than career, politician.

Tayo also gained employment at the UK Borders Agency and quickly rose into a manager post. Sadly his health issues forced him to resign in 2014, after his second election to the council.

He fought a long battle with his health after this and sadly passed away in January this year. He is remembered lovingly by his family, friends and all the Brent councillors as well as the communities in Kilburn and Brent where he lived and worked to improve lives through his casework, council work and the local services he was involved with.

Alice Allison

By Iyamide Thomas

Tribute speech given by Iyamide Thomas, Sickle Cell Society NHS Engagement Lead at celebratory event held for Alice by Croydon Sickle Cell and Thalassaemia Support Group: Firstly, may I say how sad we were to learn of Allison's



untimely passing. When I joined the Society in October 2004 I was the Regional Care Advisor for South London and it is in that capacity I met Alice and the rest of Croydon Sickle Cell and Thalassaemia Support Group members such as Annie and Bonnel.

I met them quite early as I was invited to their Annual General Meeting within weeks of joining the Society. I can't remember who was Chair of the group then but one thing I do remember from attending the Annual General meeting is that I got a parking ticket since I didn't realise Croydon Council had changed their parking rules and extended the hours! Since my initial meeting with Alice and the group I have always held the group in high regard for the great work they do.

As RCA I regularly attended Croydon Support Group's monthly meetings and their other events and can say firsthand how dedicated Alice was to the group. Her slow and measured way of speaking to me always meant she put thought into what she was saying so people would understand what she meant. She led a support group that to date has engaged most with the Society, having a presence at our Annual General Meeting, patient education days, annual Church Service etc, even if she herself did not make the events, I guess because they were on Saturday or Sunday. She led a group which worked hard to support people with sickle cell disorder and came up with innovative ideas such as the gift pack for people in hospital.

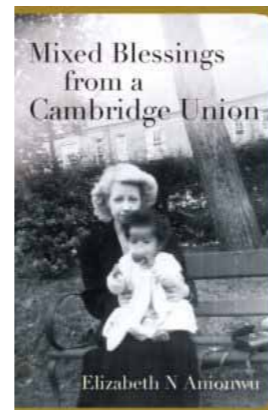
I attended the fitting funeral service that she was given and felt honoured to see that one of the photographs in the order of service was one I had taken with Alice at the group's sponsored walk. I am sure her contribution as Chair to the support group will never be forgotten and her legacy will live on.

May she continue to Rest in Peace.

Mixed blessings from a Cambridge union

Professor Elizabeth Anionwu CBE has been with the Sickle Cell Society right from the beginning: she was with us when we were first set up in 1979, and volunteered her time raising awareness and providing information for many years. Even after stepping down from the Board, she has been a long-time friend to the Society and is currently a Patron. She has also been instrumental in improving sickle cell services, working hard for the sickle cell community as the only nurse in the first centre for Sickle Cell and Thalassaemia Information, Screening and Counselling here in Brent, and having chaired projects for the Screening Programme over the years. She received a CBE for her services to nursing in 2001, having previously turned down an MBE in 1985 because she did not feel the government was doing enough for the sickle cell community.

Elizabeth Anionwu's services to the sickle cell community alone make her a noteworthy and fascinating woman, but that's only part of the story. She has lived a fascinating life, from growing up among nuns to successfully campaigning for recognition of Mary Seacole in the form of a statue. You can now read her history in her own words in her new book, "Mixed Blessings from a Cambridge Union".



Mixed Blessings is a personal memoir, full of warmth and love, insight and truths. Woven into her personal story is a social history of growing up mixed race in the 1940s and 50s, along with a look at how nursing has changed over the years: and how Elizabeth herself made the changes she needed to see. Elizabeth's life has not been without challenges, and yet she has overcome so much. Mixed Blessings is a gripping and inspirational read, showing just how much can be achieved by anyone, from any background. We at the Sickle Cell Society recommend it to anyone: you are bound to find something to relate to and something to inspire you in equal measures.

We are grateful to Elizabeth Anionwu for fighting our corner for decades, and are proud to know her. Mixed Blessings From A Cambridge Union can be purchased from Amazon or Waterstones.

Thanksgiving service 26th June



Iyamide Thomas, Ellen Thomas, Cllr Jaffer and Kye Gbangbola



Rev Canon Stephen Coulson, Cllr Jaffer and John James

The Sickle Cell Society's annual Thanksgiving Service took place on Sunday 26th June at St Mark's Church, Kennington. The theme was Sickle Cell And The Family.

Reverend Canon Stephen Coulson led the service, and guest preacher Pastor Christian Parker also offered words of wisdom. Gospel reggae artist Joshua Kesler offered up praise in the form of music. Society team members Iyamide Thomas, John James and Vice Chair Michelle Salter raised awareness of sickle cell and how it affects families.

Two readings were given. Benefits specialist Daniel Nyakutsey read Ephesians 3 verses 14-21, a prayer for spiritual strength. Sickle Cell Society Patron and EastEnders star Ellen Thomas read Genesis 13 verses 1-8, about how we are all truly family.

In attendance was the Mayor of Lambeth, Councillor Saleha Jaffer.

The thanksgiving service allows us to come together as a community and, as our offertory hymn proclaimed, to "count our blessings"!

Ellen Thomas becomes a patron for the society



Ellen Thomas, who currently plays Claudette Hubbard in EastEnders, and has previously appeared in Teachers, Holby City and Doctor Who, has become a Patron of the Sickle Cell Society.

Ellen says: "I'm excited to be working with the Sickle Cell Society as a Patron. Supporting the sickle cell community is a cause close to my heart, and I've been a long-time supporter of the Society's work. To me, it's really important to raise awareness of sickle cell disorder and the specific needs of families affected by it. I'm looking forward to doing what I can for the Society and helping out where possible."

Thank you, Ellen. We're just as excited to have you working with us!

The Kavele Kerr-Campbell memorial garden



Kavele Kerr-Campbell sadly passed away in October 2015 from complications of sickle cell disease. His mum, Simone Kerr, has embarked on a fundraising project with the Sickle Cell Society. Simone also volunteers with the Society.

Kavele's school, Leopold Primary School (Gwenneth Rickus) has organised a memorial garden for Kavele. The garden will open on 8th May 2017, on what would have been Kavele's eighth birthday. It will be a reflective, quiet space for the children, which may eventually be used as a counselling space.

As part of the fundraising campaign in memory of Kavele, Simone has teamed up with headteacher Mrs Kendall and deputy head Mrs Cheltenham. The school will be holding a superhero fancy dress event to raise funds and remember Kavele.

We're hugely grateful to Leopold Primary School and Simone Kerr for their generosity towards the Society.



Fundraising Update

On 15th October, Davina Allen organised a memorial ball in Preston, Lancashire, to celebrate the life of her brother Franklin. The ball was well-attended, and raised over £1300 for the Sickle Cell Society. In August, Davina and her family completed a sponsored walk for the Society. Thank you so much, Davina!



Davina and the team at the ball



A custom cake, fit for a ball



Savannah and Jacob, children of Board member Sheree Hall, have been fundraising in their schools! Both of the children organised non-uniform days in their schools, and educated their classmates about sickle cell. Jacob's school raised £188, and Savannah's school raised £837.86. Well done, both!

Remember back in May when we had our BBC Radio 4 Charity Appeal, starring Malorie Blackman? The numbers are in, and over £3000 was donated by listeners. The appeal was listened to by thousands, up and down the country, raising awareness to new audiences.



Exhausted after a 13 mile sponsored walk... that's a half marathon!



The Uhuru International Foundation make a kind donation to the Sickle Cell 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, and are working with Brent CCG to provide a more intensive advice and support service for Brent residents, and are hoping to secure funding to extend these services. We provide 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/donate/become-a-member

Charity number: 104 6631

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