Sickle Cell Society Newsletter Winter 2015

SICKLE
CELL
SOCIETY

Contents

A MESSAGE FROM THE CHAIR

Welcome to the Winter 2015 edition of our ever popular Sickle Cell Society Newsletter. As usual it is packed with information as befits our role as the 'Voice of the Sickle Cell Community'.

Winter is traditionally a difficult time of the year trying to stay fit, well and warm. So please accept this offering as a distraction and an opportunity to focus on goodwill to everyone for 'tis the season for enjoying family, friends, giving, and kindness.

The Society would like to appeal for you and your friends and family to join and become members of the Sickle Cell Society. I would like to introduce why membership is important and invite you to comment back to me on info@sicklecellsociety.org. Rest assured I will respond. The Society will be reviewing its terms of membership in the coming months.

To be credible as your voice we need your names, we need to be able to count all people with SCD (Sickle Cell Disorder) as supporters of the Society's work, we need to be able to show we embody a membership, a family of people with a common goal, visible to anyone who would ask the size of our membership as a measure of our mandate. Being blunt, I want you to help me capture everyone in the UK with SCD as our members. Your feedback on this challenge is most welcome, your ideas and contributions on how you can help would be appreciated. Its time to get serious, work stronger together and build representation worthy of the advocacy we provide.

The Society's mission is to assist and enable individuals with SCD to realise their full social potential and economic potential.' Those that were able to join us at our last AGM; which numbered nearly 200 people were able to hear and discuss the Society's good performance in the 2014/2015 financial year.

The Society has focussed effort to improve its finances and sustainability have started to bear fruit resulting in a surplus in an extremely challenging financial and operational climate. We also launched 2 new services on United Nations World Sickle Cell Day; one for Pre Hospital Admission Support and another for Post Hospital Discharge support, these build upon clinical relationships with CCG's (Clinical Commissioning Groups), Our website www.sicklecellsociety.org is making our work more visible and is active in bringing donors and sponsors to support our activities, it also streams some of our more recent media activities, thanks to our new Communications function so follow us on Facebook and Twitter @SickleCellUK and come to our events promoted on our website event pages. Our information continues to be high quality and independently audited by the NHS Information Standard.

In this year we have continued to improve the organisations profile, build stronger networks with support groups and regulators including the NHS Screening programme, NHS Blood Transplant, Quality Review Services, CCG's etc, and continue to develop Board Member skills and commitment.

I would like to thank our staff and volunteers for enabling the Society to punch above its weight. And this is precisely why it is time to tell the good news up membership and become a voice to be reckoned with.

We invite your feedback to this and any of the articles in this issue, contact us at info@sicklecellsociety.org

Enjoy our offering and thank you for supporting the journey we are on.

Kye Gbangbola MBA FCIOB CIHCM EurBE GDA MIEMA CEnv GACSO LCSAP

Chairman - Sickle Cell Society

Celebrating World Sickle Cell Day in Wembley

The Sickle Cell Society loves a good party and on June 19th - World Sickle Cell Day - we had a lot to celebrate: we were launching our new service for Brent residents, the Brent Sickle Cell Advice and Support Service.

It was only fitting, therefore, that we celebrated in Brent: specifically, The Drum At Wembley, inside Brent's civic centre. Two key Brent politicians joined us in the festivities, Cllr Muhammed Butt (leader of Brent Council), and Dawn Butler MP (Brent Central). Dr Ajit Shah was there to provide a GP's perspective, while representatives from The Picker Institute were also present to encourage patients to record their experiences using a new tool (see more on page 12 - first national survey closes for analysis)

As always, it was of vital importance to us to centre the views of the sickle cell community, so our entertainer for the day was Caro Ohemaa, who provided her perspective as a patient through emotional poetry. At the end of the event, the floor was opened, and patients were empowered to talk about their experiences.

Dawn Butler, MP for Brent Central, opens the event

Cllr Muhammed Butt, leader of Brent Council, speaks about Brent issues

Comfort Ndive and Sharon Jackson introduce the Brent service

THE CHILDREN'S HOLIDAY (1ST - 8TH August 2015)

By Comfort Ndive


Our volunteers are vital to making the holiday happen


A selfie with Philip Udeh!

Another spectacular year for the annual Children's Holiday 2015. The Society has continued to maintain its yearly tradition to ensure that children living with sickle cell disorder, a chronic debilitating long-term condition from all over the country come together to enjoy a week's break away from their parents and other siblings to meet and make new friends, share experiences and have great fun with others who also suffer from the condition.

We were back again at King's Park as the children thoroughly enjoyed their stay the previous year. Kings Park provided us with very comfortable en-suite accommodation and their catering was first class, with a variety of fresh and delicious food to choose from. They have a spacious indoor lounge with facilities for games, such as pool table, table tennis, and also a fantastic Indoors Sport Centre available to use (at extra cost). The holiday took place 1st - 8th August 2015. We took 28 children between the ages of 7 - 14 years old. We used our usual selection process whereby application forms are sent out to Specialist Nurse Counsellors through their professional body STAC, and also to some Sickle Cell and Thalassaemia Centres all over UK, asking them to nominate children for the Society's annual Children's Holiday. These children must come from a background where they experience isolation due to their Sickle Cell disorder. Most have never had a holiday, and as well as being a positive experience for the children, the parents also benefit by having a week's respite from the stress of caring. This one week is free of charge but we welcome payment from families who can afford it.

It was great having our regular, committed and dedicated volunteers and also some new young ones who all gave us their time to support the Society's Children's Holiday. It was great having Philip Udeh, one of the members of the Board of Trustees as a volunteer this year. We were privileged again to have among us Dr Nellie Adjaye, (retired Paediatrician), as one of our Medical Team. Having someone like her with us is clinically significant and of great importance. This year some children suffered minor and severe crises which were managed well by our resident doctor and nurses so that there were no admissions into hospital.

We were pleased to welcome the CEO John James and the Chairman of the Society Kye Gbangbole who came for the whole day on Thursday and had a great time playing games with them.

Donate to the 2016 Children's Holiday, or become a fundraiser at

http://bit.ly/ChildrensHoliday2016

The CH 2015 team!

ACTIVITIES

This year the children went to Drayton Manor Park, everyone's favourite theme park with a host of fantastic family entertainment, parked with great rides and attractions. The feedback from the children showed they had great fun and greatly enjoyed themselves. All the children and adults had a good time. The Arts and Crafts sessions were an area where the children were able to display their creativeness. The children painted pots, glass panels and T-Shirts as well as making masks and bead-work key rings. These were all displayed at the end of the week and prizes given for the best ones.

On Friday, the last night of the holiday, we held a DISCO and an X-factor show. The children were very excited as it was their last day, but at the same time they were all apprehensive as they would miss their new friends and their carers that they had come to know well over the week. The Disco night is usually one of the highlights of the holiday which the children look forward to with great excitement. They all wore their best outfits and the boys looked fantastic and cool. They all danced the night away. For the X-Factor, the carers were entertained by the children performing dancing, singing and drama in groups. Wow! Wow! There was great laughter, humour and hilarious fun in the room, what a great night that was.

TRAINING SESSIONS

(Education, Awareness and Managing your condition)

We have continued to maintain the training sessions as one of the activities held during the Children's Holiday. These sessions have a significant impact in empowering the children to be independent, enabling them to reach beyond their illness and discover joy, confidence and a new world of possibilities. It has proven to be very positive, an excellent way of engaging the children into expressing themselves and learning new things, not only about themselves but also about their condition and how to manage their illness. They learnt for example why they had to drink lots of fluid (especially water), the importance of rest, transition into adults and most importantly the names of the medications they take and why they take them. These training sessions were conducted by Dr Nellie Adjaye, (Paediatrician) and Hilda Castillo-Binger and Esther Ifinnwa (Specialist Nurse Counsellors). The children were divided into two groups the 11 - 14 years for the boys and 10 - 14 for the girls. The younger ones also had a training session suitable for their age group then joined the others later. Jayson who lives with the condition was able to talk about his experience to the boys, acting as a role model and he was supported by Leroy Lawrence. The girls' session was conducted by Dr. Nellie Adjaye and Specialist nurse counsellor Hilda Castillo-Binger. During these sessions the boys discussed issues such as paresis, bed wetting, medications, changes from young man to manhood (transition period), and relationships, very important for them to know. The girls also discussed relationships and all girl-talk, including hygiene, beauty and makeup.

Self-managing sickle cell: A patient education day in Bristol

On April 18th, the Sickle Cell Society held its first patient education day of 2015. The theme was 'self-managing sickle cell', and the city was Bristol. It was very well-attended: patients, carers and even some clinicians attended from as far away as Guildford!

The first speaker was Anndeloris Chacon, clinical coordinator for the region's community care. Anndeloris had a strong hand in organising the day, and was responsible for picking the theme, the venue and speakers suitable for the audience. Her own talk focused on why people living with sickle cell should have certain tests for things like heart function, eye function and haemoglobin count. Anndeloris stressed the importance of knowing what is normal for you, so you can seek medical attention if it deviates from your own norm.

Next up was Dr Colette Reid, a specialist in palliative care. She talked us through pain medication for sickle cell, and what side effects you might encounter. Did you know that when you are given morphine, you should ask for laxatives? Did you know that ketamine isn't just for horses... it can be an effective drug for humans, too!

The final speaker was Dr Dorothea Dayley, who discussed nutrition and lifestyle factors in sickle cell. She taught the four pillars of health: relationships, nutrition, environmental hygiene and detoxification. Following the old adage 'an ounce of prevention is worth a pound of cure', Dr Dayley provided constructive ways of keeping yourself healthy and hydrated.

More details about the event and what we talked about can be found on our website.

Thanksgiving church service 2015

By Iyamide Thomas, NHS Outreach Project Lead

This year the Sickle Cell Society's Annual Service of Thanksgiving and Remembrance paid its third consecutive visit to South London although this time around it was held at St Marks Church Kennington in Lambeth. The service held on 21 June was to commemorate World Sickle Cell Day (19 June) but as 21 June was also Father's Day in the UK our theme was 'Men and sickle cell'. Would the clash with Father's Day mean that some would not attend? Indeed this was the situation for some but nonetheless the event attracted a good crowd and amongst approximately 80 attendees were several fathers and some very distinguished individuals such as Councillor Donatus Anyanwu (Mayor of Lambeth), Councillor Dora Dixon-Fyle (Mayor of Southwark) and celebrity actress Ellen Thomas (Eastenders). In addition to members of the Society, service users and friends, the sickle cell nurse specialists (particularly those in South London) turned up in full force to support the Society, as did Dr Allison Streetly, former Director of the NHS Sickle Cell and Thalassaemia Screening Programme. An insightful address was given by our guest preacher Pastor Dada Ayeni whilst Mr Collins Pratt and his group rendered some very enjoyable Negro spirituals on their saxophones. After what many described as an enjoyable service there was the usual networking and refreshments before many began the easy start to their journeys home from Oval underground station conveniently located across the road; a bonus for a return to the same venue next year perhaps!

Iyamide Thomas of the Sickle Cell Society (second from right) with Councillor Donatus Anyanwu, Mayor of Lambeth and SE London Sickle Cell and Thalassaemia Centre staff

The Sickle Cell Society vs Hollywood

This summer, film fans might have left the cinema with a very negative impression of sickle cell disease thanks to popular movie TED 2. The flick featured a deeply unpleasant joke about sickle cell, tapping into racism and disablism, as well as spreading misinformation about sickle cell.

Together with our Scientific Adviser Professor Simon Dyson of De Montfort University, we took action. We wrote a letter to Universal Studios, outlining what was wrong with the joke. You can view the full text of the letter at our website.

In September, Universal Studios got back to us, and offered us a teleconference to discuss the matter. Our CEO John James, Professor Dyson, Craig Robinson, Chief Diversity Officer at NBC Universal; Peter Cramer, President of Production at Universal Pictures and Cindy Gardner, Senior Vice President, Corporate Affairs at Universal Pictures talked about the letter, and steps forward. The studio executives took the matter very seriously.

That month, Universal aired educational segments about sickle cell as part of the USA's awareness month. The thinking behind this was to try to right the misinformation and stigma they had allowed to be spread in TED 2.

It was a good start, although we have further to go. As Professor Dyson said: "It is good that some key messages have been put across, including that sickle cell can affect any ethnic communities and is not a "black disease". The pieces also emphasised that with good social support, people with sickle cell disease can achieve great things and that, with proper social support and medical care, people with sickle cell disease can live into their eighties.

"The coverage also notes the challenges, such as the near daily pain that may be experienced and the difficulties that adults with sickle cell disease in the USA face in getting treatment because too few haematologists in the USA take on patients with sickle cell disease.

"It's a good start, and I would commend NBC for being open to these initiatives, but we really need people to get beyond the basic medical facts about sickle cell disease and see that there are social challenges too, like how to ensure young people with sickle cell get the best education and employment opportunities and are not discriminated against by employers, or by insurance companies in terms of mortgages and travel insurance."

IN MEMORIAM

Dr Neville Clare - Pioneer Sickle Cell Advocate Passes Away

By Iyamide Thomas on behalf of The Sickle Cell Society

The Sickle Cell Society was saddened to hear of the passing of Dr Neville Clare M.A. PhD on 20 July 2015. Dr Clare who was 69 was a pioneer in raising awareness of sickle cell disease in the UK and advocating on behalf of those with the condition. He himself had sickle cell and was passionate about the sickle cell cause. In 1976 Dr Clare launched one of the first ever sickle cell organisations in Britain to promote sickle cell research and awareness. It was called the Organisation for Sickle Cell Anaemia Research (OSCAR) and from its early beginnings in Wood Green several OSCAR branches subsequently emerged both in London and nationwide. On hearing the news of his death Comfort Ndive of the Sickle Cell Society said: 'His immense contribution to the world of sickle cell has been a great inspiration to many of us. He would be sadly missed. He supported the Society's Hackney Sickle Link Project in Hackney when we had an Open Day in Hackney Town Hall in 2001. He was always willing to share his experiences and knowledge of what sickle cell is and how it affects people living with the condition'.

In 2007 Dr Clare published his book aptly named 'An Oscar for my troubles - A Life Working for Better Understanding and Treatment of Sickle Cell Disorder'. In this very interesting book Dr Clare reveals that he wanted the name of his organisation to be one that would easily be remembered and the first name that came to mind was SCARE - the Sickle Cell Anaemia Research Establishment. He talked about the idea to colleagues whose feedback straight away was 'Maybe not Neville'! (He goes on to say there was actually an organisation in America with that same acronym). In the Foreword to Dr Clare's book Tony Wade MBE said of Dr Clare: 'On discovering the lack of understanding there was in Britain of this health issue that affected the Black community, Neville Clare took it upon himself to research what information there was available, mainly from the USA and set about initiating a programme of raising awareness to make the problem publicly known in Britain and ensuring that it got on the public debating agenda. He drew on his own suffering and personal experience to open people's eyes to what was at stake'.

May his soul Rest in Peace

Dr Clare at Hackney Open Day

SIR WILLIAM DOUGHTY
1925-2015

By his son, Simon Doughty

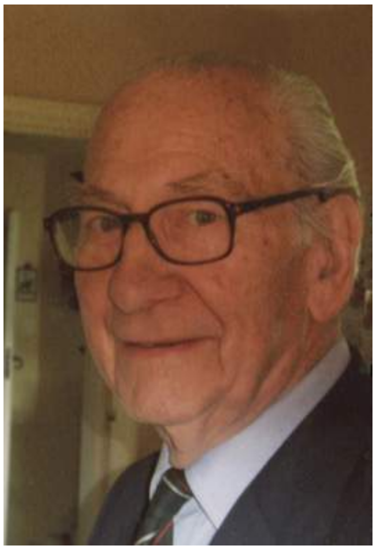
William Doughty was born in Willesden on the 18th July 1925. During his early years, he was a boy scout, an experience which helped develop his natural flair for leadership. In 1939, while playing cricket, he received a bruise on his shin which soon became osteomyelitis, an infection and inflammation of the bone marrow. In the days before antibiotics it meant months in hospital, numerous operations and daily re-dressing, and the continuing possibility of amputation. For his courage and endurance through this long illness, Bill was awarded the Scouts' highest award, The Cornwall Badge, The Scouts' VC.

Bill joined the Home Guard in early 1941, aged 15, and remembers keeping his rifle and five rounds of ammunition under his bed while dreaming of thwarting a German parachute assault onto West London. Years later he would chuckle at Dad's Army, and say that it was not far from the truth. What he really wanted was to fly with the Royal Air Force, but was unable to pass the medical, and so became an aircraft apprentice for Fairey Aviation, based at Hayes. If he could not fly then helping to build aeroplanes was the next best thing.

After the war, Bill was determined to get to Oxford. He worked hard at night school and was offered a place, but a visit Trinity College Dublin persuaded him to apply there instead. Perhaps a 20 year only girl called Lorna, who he had met at a dance in Dublin, had been a factor? He went to Trinity, read History, rowed at Henley, and was married to Lorna in 1952. The following year he left with an honours degree, taking-up a graduate apprenticeship with the Metal Box Company. In 1966, Bill attended the Advanced Management Program at Harvard Business School, later moving to Molins Machine Tool Company and, in 1969, to Cape Industries, where he became Group Managing Director in 1980.

Working in the energy business at a time of spiralling oil prices, in 1981 Bill had the idea for the Association for the Conservation of Energy. Supported by the industry, it was a great success, and is still going strong. Then, in the mid-80s, another door opened, when Kenneth Clarke, the Health Secretary, offered Bill the chairmanship of the North-West Thames Health Authority. He leapt at the chance. His time in hospital had left him with a huge respect for those who work in the health service, at all levels, and his years in industry had taught him that organisations are about people. He was perfect for the job, and was never happier than when visiting hospitals, talking to nurses, junior doctors, consultants, and other members of staff. It was a hugely rewarding time of his life.
Bill also became involved in numerous charities. Headway, the King's Fund, Great Ormond Street, and others. He enjoyed his involvement with them all, but particularly so the Sickle Cell Society. He tried, when he could, to attend the AGM, and always had huge admiration for this very special charity.

In retirement, Bill enjoyed more time with Lorna, their three sons and four grandchildren. Every year he spent a few days at Henley Royal Regatta, where he had captained the Trinity College Dublin crew in 1952. And then there was Lord's Cricket Ground, where he could often be found during a test match, sitting in pavilion, often with a friend or one of his sons. There is a corner of the Allen Stand that will be forever Bill Doughty's.



William Doughty died peacefully at home on 21st March 2015. He was nearly 90 and he and Lorna had been married for 63 years.

Black History Month 2015 showcases Achievements in Sickle Cell

By Iyamide Thomas - NHS Outreach Project Lead

When Southwark Council announced the theme for their 2015 Black History Month grant funding applications I had no doubt I would renege on my pledge to take a break after the last three successful applications, as this theme was so far up the Society's street one just had to apply! The 2015 theme was 'Fit to Achieve - how the Black community has struggled and succeeded in Britain' with sub themes that included 'promoting greater awareness of health issues prevalent in Southwark's Black community' and 'encouraging uptake of screening'. Our innovative event billed 'The Sickle Cell Story - History, Legacy, Achievements' would use film, presentations, personal stories, comedy and discussion to feature the struggles, achievements and legacy within the sickle cell 'community' and also raise awareness of this condition with a high prevalence in Southwark. One presentation would chart the history and achievements in sickle cell covering its 1874 discovery by Dr Africanus Horton (a descendant of freed Igbo slaves and the first African graduate of the University of Edinburgh), the Western discovery in 1910 in the USA and the 'struggles' of the UK sickle cell community over the past decades to raise awareness, achieve better care and equity for families affected by the condition. Another presentation would feature an inspirational figure in the sickle cell world Dr Ade Olujohungbe (1963 - 2013) who himself had sickle cell disease but succeeded in becoming a world renowned Consultant Haematologist looking after patients with sickle cell. Through personal stories from individuals such as a civil servant, a teacher, stand-up comedian and pastor living with sickle cell, service users would show that despite their debilitating condition they were also 'Fit to Achieve'.

Southwark Council thought our proposal was 'both appropriate and different from the others' and so it was that on 2 October 2015 the Sickle Cell Society succeeded in putting on the very successful Black History Month event described above as part of the Council's official 2015 Programme. Around 60 people attended the event. The Mayors of Southwark (Councillor Dora Dixon - Fyle) and Lambeth (Councillor Donatus Anyanwu) were also there, with Councillor Dora Dixon - Fyle giving some appropriate opening remarks.

L-R: Cllr. Dora Dixon-Fyle, Mayor of Southwark, Mr John James, CEO, Sickle Cell Society and Cllr. Donatus Anyanwu, Mayor of Lambeth

Sold to the man in the white shirt!

Feedback was that the event was educational, inspirational and enjoyable. People particularly enjoyed performances by Adebisi Aluko who used comedy to describe how sickle cell affected him and Caro Ohemaa who used a very insightful poem to convey experiences of some service users whilst in hospital. An important presentation was given by insurers on travel and life insurance for people with sickle cell with the hope that they can provide acceptable premiums! A fun auction including a stay for two at a top London hotel was conducted thanks to Wari of London Africa Cultural Event who donated the prizes. There was some very fierce bidding going on and alas Councillor Dixon-Fyle who also joined in the fun got outbid by the insurers!

Thanks to all who made this event a success and of course a big thanks to Southwark Council and the NHS Sickle Cell & Thalassaemia Screening Programme for supporting it.

Proceedings from the 36th AGM and Education Day

Our 36th AGM and our second education day of 2015 were held concurrently at the Grand Connaught Rooms in Holborn on July 18th. The AGM was a triumphant affair: 2014-2015 has been a very good year for the Sickle Cell Society, with us ending the financial year with a budget surplus, as well as launching several new projects. The room was jammed fit to burst with the sickle cell community: carers, healthcare professionals, academics, and most importantly of all, patients.

We were proud to award achievement. Jacky Ferguson was our Volunteer of the Year for her tireless support of the Society, and young Rahima was presented with the Black on Black award a story she wrote. Gary A. Swaby was presented with the Floella Benjamin Achievement Award for raising awareness by writing about his own experience of a near-fatal sickle cell crisis.

The topic of the patient education day was In Utero Stem Cell Transplantation, with speaker Dr Stavros Loukogeorgakis from University College London. In utero stem cell transplantation is a promising avenue that may prove to cure sickle cell disease before a baby is even born with it!

Stem cell transplants (or 'bone marrow transplants') are the only cure for sickle cell at present. They replace the body's blood-making cells with healthy blood-making cells. However, they are not suitable for everyone: donated stem cells must come from someone closely matched (a sibling) and the procedure is risky, requiring dangerous chemotherapy and the patient must take immunosuppressants for the rest of their life. The new avenue of research gets past a lot of these problems: if the transplant were to be performed on a baby in the womb at about 12-14 weeks of pregnancy, the stem cells don't have to match, and chemotherapy and immunosuppressants are not necessary. It might sound like science fiction, but this research is happening, with human trials expected soon. Read more, and download Dr Loukogeorgakis's slides at our website.

We're hugely grateful for everyone who came to the AGM and education day, and delighted by the year. As our Chair Kye Gbangbola said in his opening address, the Society has always punched above its weight... and long may we continue to do so!

Dr Stavros Loukogeorgakis answers questions about in utero stem cell transplants, facilitated by Elizabeth Anionwu

Kye Gbangbola reflects on a great year for the Society

First national survey of people living with sickle cell disease closes for analysis

The first nationwide survey of people living with Sickle Cell Disease (SCD) has now closed for analysis, with initial findings set for publication in early 2016.

Designed by the Picker Institute, the not-for-profit charity which uses people's experiences to improve the quality of health and social care for all, the development and implementation of the questionnaire was commissioned by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care Northwest London (NIHR CLAHRC NWL), in partnership with the Sickle Cell Society.

Focusing directly on patient experience, the survey asked patients about aspects of care that are important to them, including access to care services, information and support for their condition, and their views on care across inpatient, outpatient and emergency settings. Survey versions suitable for both paediatric and adult patients, and parents/ carers of young SCD patients, were available.

Having received over 600 responses (at least 200 for each version) it is the largest feedback drive of people living with the condition, conducted in the UK to date. When feedback tools are specifically tailored to the healthcare needs of a particular patient group they can be used to effectively capture and improve their given care experiences, potentially informing the delivery, design and commissioning of services. The qualitative research stage of the project informed development of a community support worker for SCD, position in North West London (an area with a high population of people living with the condition).

SCS CEO John James says, 'We have been overwhelmed by the sheer generosity of experience shown by the sickle cell community, and firstly just want to say a massive thank you to them and everyone that has worked so hard to generate responses. In the past we have heard of extremely varied care experiences from people with sickle cell, from truly inspiring exemplary care, to, what can only be described as disturbing. The new survey gives us the ability to measure experiences using a validated tool, and will allow us to obtain a wealth of data on sickle cell care, which will be a real game-changer in terms of the care improvements it could enable.

As well as inspiring grant funding for further research, the SCD survey tool will be made available for individual clinicians in England to collate relevant feedback and make service and care quality changes accordingly. Your feedback is invaluable and will make a real difference, we look forward to updating you on just how it is being used soon.'

Hydroxyurea: transforming lives of children in the Liverpool area

By Russell Keenan

Consultant Paediatric Haematologist and Lead for Clinical and Laboratory services for Haemoglobinopathies for Liverpool, Merseyside, Cheshire and North Wales. Hydroxyurea also known as hydroxycarbamide is a medicine that has been around for nearly 150 years. In the early 20th century it was used to treat some rare leukaemias and skin conditions such as psoriasis but it is not often used for these conditions today. Hydroxyurea has been used with increasing evidence in sickle cell disease for almost 25 years now. It is not a new drug that has just been invented. This long history is important as we already know a lot about this medicine from decades of use.

I will review in this article the medical and scientific literature especially looking at recent evidence in children and the long term benefits of taking hydroxyurea for sickle cell disease. Read the full article at http://bit.ly/KeenanHydrox

Get ready to be 'Dazzled' - Sickle Cell Film Premieres in the UK

By Iyamide Thomas

'Is it worth risking it all to have it all?' So asks 'Dazzling Mirage' the new sickle cell love story by renowned Nigerian Nollywood producer / director Tunde Kelani ('TK') which premiered at the Ritzy Cinema, Brixton on Saturday, 7 November as part of Film Africa 2015 Festival. Dazzling Mirage is an inspiring story of love, perseverance and hope in the face of adversity. A talented young advertising executive is in the prime of life - she's bright, her career is in overdrive, and she has a supportive and loving boyfriend. There's just one problem: she suffers from sickle cell disease. Kelani's film gets to the root of the stigma associated with this increasingly common illness, suggesting that it doesn't have to define or restrict life. The film was adapted from the book by Yinka Egbokhare. When asked what the inspiration was behind this his latest film TK stated that three things came together at the right time: he was concerned about drawing more awareness and support for sickle cell in Nigeria, he came across the book 'Dazzling Mirage' and he had previously seen 'The Family Legacy' (a film commissioned by the NHS Screening Programme to raise awareness of sickle cell disorder, the myths, stigma and testing for the condition). He then got Ade Solanke the script writer of The Family Legacy to do his screenplay. The 'sold out' premiere was followed by a short Q & A which I hosted with 'TK', Ade Solanke and Grace Lawson (sickle cell service user) as panellists. Judging from audience reaction it would be safe to say everyone enjoyed the film! This is what one sickle cell service user had to say:

'It would be great to have some more screenings. I would definitely recommend it to my family and friends (or go and see it again myself!). On a more personal level I also felt it was a good watch for my boyfriend who often doesn't know how to approach some of the topics that were mentioned in the film. He too enjoyed the screening'.

The Dazzling Mirage premiere was a one- off screening but plans are in place to organise more UK screenings early next year so watch this space!

L-R: Grace Lawson, Ade Solanke, Iyamide Thomas, Tunde Kelani

FUNDRAISING UPDATE

Our fundraisers have undertaken all sorts of diverse challenges and events recently. Here's a few highlights! We are, as always, truly grateful for their contributions.

Edgar Cornelius from EMC Promotions organised annual dance in May presenting £1,000 cheque to Kalpna Sokhal

Kirsty Lewis with her Son Kaysar completed the Big Fun Run on 31.10.15 and raised £355

Thanks to Victoria Line for organsing PicnicFun Day in Memory of Carol Osafo and raised £580.00

Coutts & Co Charity Football Match held on Friday 21st August 2015 raised £250

Eulene Gooden completed Edinburgh Marathon on Sunday 31st May raising £558.18, posing with husband and daughter.

Simon Gibson completed the London to Brighton Cycle Ride on 6th September 2015 raised £75

Norbert Edwards and Deloris Francis raised £1,072 at music cabaret at The Star of India Restaurant on 22.10.15

Thanks to our amazing Super Heroes who completed a 5k or 10K on Sunday 17th May 2015. Our runners include Michelle Lewis, Donna Williams, Errol Maginley, Sharon Salmon, Doug Smith, James Wood, Scott Linton who between them raised £1,693.63

A huge thank you to all who donated. Your generosity keeps us going.

Online Giving	35,978	Waitrose Limited Shepherd Bush Branch - Fundraising Event	350
Payroll Giving	34,128	Manchester High School for Girls - Fundraising Event	350
Mrs Comfort Ndive - Donation	5,000	Howard Chadwick Funeral Service - In Memory Of Yvette Cynthia Baptise	326
Davina Allen - Fundraising event In Memory of Caroline Williams & Franklin White	2,084	Brian O'Dea at Transport for London	301
The Freemasons' Grand Charity	2,000	Titus Ayodele at Efon Alaaye UK and Europe Ass - Donation	300
The Hospital Saturday Fund	2,000	Titilayo Adenuga - Fundraising Event	300
Mark Johnson at St Angela's Ursuline Convent School - Fundraising Event	1,450	Ellen Thomas - Donation	300
Bancroft School - Fundraising Evenet	1,259	June Nicol-Dundas - Donation	290
Zebulu Delisser at HMP Pentonville - Fundraising Event	1,077	Dr Nellie Adjaye - Donation	280
Norbert Edward, Deloris Francis, Shah Undin - Fundraising Event	1,052	Remembrance Service Collection	279
Willesden Seventh Day Adventist Church - Fundraising Event	1,027	Christ The Redeemer Parish Church - In Memory of Jean Griffiths	277
Edgar Matthew Cornelius at EMC Promotions -Fundraising Event	1,000	Judy Spencer - Fundraising Event	275
The Albert Hunt Trust	1,000	Miss Aiwan Obinyan - Fundraising Event	270
Christina Morris at Ealing Hammersmith & West London College - Fundraising Event	856	Pride of Islington Lodge No. 3994 - Donation	250
Francis Folorunsho - Fundraising Event	757	Janet Rochester - Fundraising	250
H Bolade & D Nkain Njini (Mr & Mrs Bolade) - Celebration of their Wedding	700	Emmanuel Methodist Church - Donation	250
Amber Owen - In memory of Carl Osafo	580	Tabitha Daniels-Moss at Winning Moves UK - Fundraising Event	250
Ms Lucreta La Pierre - British 10K London Run 2015	579	Global Blood the Rapeutics - Post Text	243
Mrs O F Brown - Donation	560	R Davies & Son (Dignity Funerals Ltd)	236
ATL - Suzanne Griffith	552	Father Nigel Priest at Christ the Redeemer Parish Church - Donation	213
Alma Jean Henry Charitable Trust	500	Anne McKeegan - Donation	200
Bishop Stopford's School - Fundraising Event	400	Jennie Dighton at Peterborough Operative & Drama Society - Fundraising Event	200
J E Hackett & Sons Ltd - In Mem of Karen Diane Maynard	400	Mrs Patricia Turner & Mr Clifton Turner - Donation	200

SICKLE CELL SOCIETY

Brent Sickle Cell Advice and Support Service (Brent SCASS)

NHS
Brent
Clinical Commissioning Group

Do you live with a Sickle cell disorder?

Do you need advice or support?

Do you live in the Borough of Brent?

If so, we would like to hear from you...

We will provide

- Signposting to other services including introduction to a local Sickle Cell Support Group
- Practical help (such as light shopping, collecting prescriptions)
- Emotional support and encouragement of self care
- Advocacy

How can I access this service?

Any health or social care professional can refer you to this new service. Self and carer referrals will also be accepted.

For more information contact:

The Sickle Cell Society
54 Station Road
London NW10 4UA
Telephone: **020 8961 7795**
020 8963 7795
07841 558612

Email: **info@sicklecellsociety.org**
Website: **www.sicklecellsociety.org.uk**

Brent Sickle Cell & Thalassaemia Centre
Central Middlesex Hospital
Acton Lane
London NW10 7NS
Telephone: **020 8453 2050/52**

Website: **www.sickle-thal.nwlh.nhs.uk**

Brent SCASS
Email: **brentsicklecellservice@nhs.net**