Sickle Cell Society Newsletter Summer 2015

SICKLE CELL SOCIETY

Contents

A MESSAGE FROM THE CHAIR

Kye Gbangbola MBA FCIOB CIHCM EurBE GDA MIEMA CEnv LCSAP

Welcome to the Spring 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'. At the outset I thought it might be helpful to outline our work at this time.

We continue to aim for a cure whilst focussing on better palliative care to improve the quality of life for our patients and their families whilst reducing costs to the NHS through better community responses that reduce the need for admissions.

We continue to drive Sickle Cell Disorder (SCD) up the political, public and medical agenda. We continue to engage in hospital peer reviews, and instigating research. We work with NHS Commissioners, specialised clinicians, expert patients, and public health representatives to improve contracted medical service responses to sickle cell disorders, Thalassaemia, and other Haemoglobinopathies. To address the range of quality and efficiency improvements needed, a clinical performance 'Dashboard' has been formulated to assess the services provided by hospitals with 'Specialised Haemoglobinopathy Centres'.

I am pleased to report the Society's recent focus on financial control and fundraising is delivering good results and improved financial performance even in these very challenging times of private and public cuts in funding and investment.

Research has shown discrimination and inequalities issues continue to have adverse impacts on patients and their families. The Society is taking concrete actions through Parliament and the APPG (All Party Parliamentary Group) for Sickle Cell Disorder and Thalassaemia to address this serious and significant problem.

The Society is constantly striving for better data to set strategy, set goals, measure performance, and manage change. The Society was central to the founding of the NHS Sickle Cell and Thalassaemia Screening Programme which has evolved into the Antenatal and Newborn Screening Programme. The objective was to provide information to make decisions on the scope and range of national services, training and education needed. The UK screening programme was a first in the world, but it is now found in the most progressive countries for medical practice. The programme has revealed the changing demograph of the disorder, it is now apparent there are increasing numbers of white babies being born carrying the gene for sickle cell.

We are looking to progress the legacy of our dearly departed Ade Olujohungbe by updating the Adult Care Standard and launching a new award in his honour.

The Adult Care Standard provides a robust structure for health and social care professionals to deliver high quality, equitable and accessible services across the country. The Standard should also be used by patients, carers and family members to be aware of what service they have a right to no matter where they are in the country.

The Society's Regional Care Advisors; Comfort Ndive and Iyamide Thomas, continue to provide excellent advocacy and outreach services across London. They were recently featured as Saint's on the popular BBC TV programme Saints and Scroungers. We continue to try and replicate these innovative services which make a significant difference in the management of this chronic condition, but we recognise the limitation of working in these difficult fiscal times of reduced funding across the country.

We have just secured the new version of the Information Standard a credit to the organisation and proof positive of the Society's ability to punch above its weight. Though the Society has had the 1st generation of the Standard for several years, our achievement of the new standard was aided by the helping hand of Sandy Forsyth from the British Liver Trust. The Society has recently been joined by Zoe Williams in the role of Communications and Media Officer. I am always grateful to our CEO, volunteers and staff who work tirelessly

in the service of SCD.

I would like to acknowledge the ongoing support we receive from our network of support groups, NHS England, Brent Council, and Novartis. And a special thanks to all the individuals, volunteers, and other organisations who have raised funds on our behalf.

Let us together continue to forge ahead addressing all the issues pertinent to our care and welfare with our many supporters at home and abroad.

And please remember to come along to our regular patient education days. Past training has included Pain Control, Screening and Pregnancy, Sickle Cell Trait, Understanding new NHS Commissioning, Iron Chelation, Adequacy and Safety of Blood Supply, Cures and Stem Cell Transplantation, Nutrition, etc many are available on our website **www.sicklecellsociety.org** The Society's Patient Education Days are well attended and happen across the country, the next will be in London, following our AGM.

The Society's exists to care for and protect the interests of people with Sickle Cell. I urge all people to become Members of the Society. It is the members that provide the mandate for our existence, that give us the right to be the voice of the Sickle Cell Community. Sign up and remember membership is not restricted to people with Sickle Cell, all people are welcome with and without the disorder.

We need your support to progress our work. We need to restore welfare funds to help people in need. We need to provide respite services, publications, advocacy, befriending, Information Lines, guidance and support to organisations, support of affected individuals and their families. We also need respond to and influence national Haemoglobinopathy policy, work with support groups, deliver and participate in education, training, and events. In addition the Society has flagship activities with the Annual Childrens Holiday (30 Children, 15 carers and at least 2 trained Nurses), and support to Expert Patient Programmes, plus so many other initiatives the Society gets involved in for the Sickle Cell community. Money raised must also pay for salaries and administration. As they say 'there are no free lunches' and all this work comes at a cost, we rely on the kindness and benevolence of you and the public to raise much needed funds.

How can you help? You can make a donation; on our website or by post, make monthly contributions, no amount is too small. Many get sponsored in charitable sports events; running, walking cycling to name just a few. In this time of Corporate Social Responsibility people have approached colleagues and friends to give sponsorship donations, pro-bono work, and time/services in-kind. There are those special people that put on events, others take buckets out to collect money. Some of the greatest contributions to the cause have been made by individuals who have taken up the challenge to make a difference. Never believe the myth that you can't make a difference.

The role of chair carries a great deal of responsibility. It is essential that we build the best and most sustainable staff and Director teams possible, one capable of creating short medium and long term growth within the business environment they find themselves. I am pleased to report the organisation is in safe hands, reputation and credibility are growing and the Board and Staff are focused on its goals and objectives. I am however saddened by my own recent injuries which prevent my previous more physical participation in the Society's work. In honour of my young son Zane, who cared about the Society and its people, I will get on with it and do what's right, do what I can, and then some, with the support of the Board, and staff, and you.

So as we move towards the Society's 4th decade of operation I take this opportunity to thank 'Members' old and new, there are some great names amongst them, we are forever grateful for their contributions and our door is always open to welcome old friends.

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

A MESSAGE FROM OUR CEO JOHN JAMES

I would like to take this opportunity, whilst we are not even halfway into 2015, to extend my good wishes to our supporters, staff, volunteers, stakeholders and friends to wish you a happy and successful 2015.

The last financial year 2014/15 has been another challenging year in many ways for the Sickle Cell Society, not least because of the tough economic climate in which we operate, NHS transition and change. Nonetheless it has also been a year of great progress and achievements which is a credit to our staff and volunteers in particular, who have been admirably supported by our Board of Trustees.

The strategy over the last 2 years has been focussed on addressing urgent operational and financial priorities within the Society, particularly restoring our financial sustainability going forward. We have made sound progress with this but there is still work to do. This focus has not stopped us from other important accomplishments during the year as follows;

- Another successful Children's holiday 2014 in Northamptonshire
- The launch of a new Sickle Cell Society website- for which we have received positive feedback
- A successful Patient Education days- covering self-management of sickle cell
- Making significant progress with our finances ending the year 31 March 2014 with a small deficit
- A well attended and participative Annual General Meeting
- Establishing a new roundtable Forum with other smaller Sickle Cell organisations across the country to share information and experiences

I am particularly delighted that this year priority has been given to producing this Society Newsletter via a digital on line version. This is a first for us and over time we will gradually replace the printed versions of our Newsletter. We have ambitious plans lined up for the coming year whilst maintaining our focus on our financial and operational priorities.

The progress we have made over the past two years would not have been possible if we did not have people (supporters, staff, volunteers, stakeholders and friends) who are passionate about sickle cell. It is a pleasure to work with them and I look forward to continuing that relationship so that together we can create an exciting future for the Sickle Cell Society and people with SCD and their families.

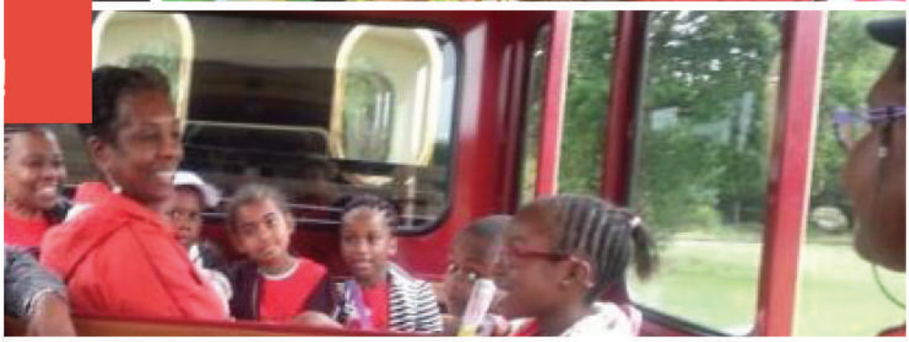
News from our Summer 2014 Children's Holiday!

Every year the Society takes a group of up to 30 children aged 7 to 14 years for a week's holiday. The children are nominated by a health professional at the clinic or sickle cell centre that they attend and come from all over the UK. It is funded by grants and donations, and every year it is a challenge to make sure we get value for money whilst still giving the children an exciting time away from home. We aim to give the children a week of fun and games with an opportunity to make new friends. During the week, we also run some educational sessions, talking to them about living with Sickle Cell, teaching them to learn to manage their condition and empowering them to be independent. They learn for example, the importance of drinking plenty of fluids, transition into adults and the medications that they take.

As well as benefitting the children themselves, their parents/guardians also get a well-deserved break from the stress of caring for them and more time for themselves and their other children.

In 2014 the Children's Holiday proved to be yet another exciting week. This time we took 23 children between the ages of 6 and 14 years old to Kings Park in Northampton on 2nd - 9th August 2014. It is a modern purpose-built conference centre with very comfortable en-suite accommodation and good food.






During the week we always try to schedule at least two trips away from the centre to places such as theme parks, zoos, bowling, laser games, museums etc.

This year we spent a day at Wicksteed Park (a theme park with rides to suit all ages) and an afternoon at the local bowling alley. The trips are always very popular with the children but expensive, so the more donations we receive the more trips we can include.

Even while at the centre, the time is filled with plenty of activities to keep the children occupied. We run several Arts and Crafts sessions where they can display their creativeness in activities such as T-shirt painting, glass painting, mask painting, and making bead work key-rings. All of the items are displayed at the end of the week and prizes are given for the best ones voted for by the children themselves. The end of the week also marks the time to hold the traditional Talent Show and Disco. The children practice their acts during the week, including singing, dancing, magic and short plays, and perform them on the last evening before going home, followed by the prizegiving ceremony and Disco.

A holiday such as this relies on having committed volunteers who act as carers to the children. Without their dedication and enthusiasm, we would not be able to continue this tradition. We aim to have a ratio of one carer to two children if possible, but this relies on having a large pool of volunteers. Our pool of volunteers also includes nurses and a doctor who make sure the children continue to take their regular medications and are there to treat any (fortunately rare) medical emergencies. We particularly need to recruit more male volunteers and more young volunteers who can act as role models for the children. As the holiday is held during the school's summer vacation, we would also welcome any teachers who would like to join us.

The holiday turns sickles into smiles, providing respite for carers, and the children get a lot out of it. Michelle, age 9, says: 'I had a wonderful time meeting other children in the same situation like me, we shared our experiences together which boosted my confidence'.

Bolaji, age 12, says: 'I learnt that I am not the only one that has sickle cell. It's good to know that I'm not alone and I can hang around with people who understand me'.

VOLUNTEERS REQUIRED

Have this article and the photos of the Annual Sickle Cell Society Children's Holiday inspired you to become a volunteer carer for next year's holiday? The carers have just as much fun as the children!

We urgently need to enlarge our pool of adult volunteers to help us. Any age, male or female. You are all welcome. The holiday lasts one week but we will welcome anyone who can help for at least 3 or 4 days.

Please contact the society and ask for an application form:
Tel. 020 8961 7795 or 020 8963 7795
Email: comfort.ndive@sicklecellsociety.org

HOW TO APPLY FOR YOUR CHILD(REN) TO ATTEND THE ANNUAL SICKLE CELL CHILDREN'S HOLIDAY

The Society does not accept direct applications. These must be made via your local clinic or Sickle Cell Centre.

Please ask one of the health professionals to nominate them.

Applications are invited to be sent into the Society between April and June 2015

Our children's holiday is funded entirely by generosity. We need to raise £25,000 to give these children the best summer holiday. To donate, please text CHFD48 £3 to 70070. Donate online. Visit our fundraising page:
www.justgiving.com/Sickle-Cell-Childrens-Holiday

COALITION WORK

The Sickle Cell Society participates in coalition work, working with other organisations to achieve our goals.

Here's some of the projects our coalition partners have undertaken:

Genetic Alliance UK
Supporting. Campaigning. Uniting.

The Genetic Alliance, of which we are a member, has published a new patient charter, addressing issues it has identified with how medicines for rare conditions are considered for NHS funding. It noted that patients in England are often prevented from accessing the medicines they need because NHS England's commissioning arrangements are, overburdened, and under-resourced. The commissioning arrangements cause delays in access to potentially life-saving new medicines on the NHS.

86 groups, including the Sickle Cell Society, endorsed the patient charter, which provides six recommendations for improving the situation and ensuring fairness for patients with genetic conditions:

1. All seven of the appraisal and commissioning routes for rare disease medicines should be considered objectively
2. Greater patient voice is essential in decisions as to what should, and what should not be commissioned by NHS England
3. NHS England and the patient community need to work together to strategically address the financial sustainability of the commissioning of rare disease medicines
4. For NHS England to fulfil its organisational promises to be 'open and transparent', 'prioritise patients in every decision' and 'listen and learn', it must optimise existing communications and engagement platforms
5. NHS England's Clinical Reference Groups should be granted additional resources to support their ability to give expert advice, and enable consistent decision-making and effective stakeholder engagement
6. NHS England's appraisal process needs drastic streamlining and rationalisation to enable timely, patient-focused and transparent commissioning of rare disease medicines

We have also worked in collaboration with Rare Disease UK, an offshoot of the Genetic Alliance. Rare Disease UK have released a report about transition between care providers. We have known for some time from patients and their families as well as clinicians that there are significant challenges for young people in transition between care providers.

RARE DISEASE | UK

Young people with rare diseases must move from paediatric to adult care, and the report highlights a number of challenges they face, including:

- A lack of age-appropriate services for adolescents
- Insufficient training for medical professionals
- Transition coming as a shock for patients
- Parents feeling unsupported

These challenges apply to young people with sickle cell and those with rare diseases. The report also noted that transition tends to be better for those with common conditions.

Case studies are provided to show best practice for transition care, addressing the problems highlighted.

The Sickle Cell Society is a member of the Prescription Charges Coalition, the campaign to exempt people with long-term conditions from prescription charges.

From April 2015, charges rose to a crippling £8.25 per item.

So far, roughly 20,000 people have participated in activities such as writing to MPs and signing a petition to show support for fairer prescription fees.

Meanwhile, the Prescription Charges Coalition has given evidence to the Health Select Committee Inquiry into Public Expenditure on Health and Social Care in October. The evidence:

- Calls on the Government to consider the health, economic and societal evidence for extending to all long-term conditions the current medical exemptions for prescription charges
- Highlights that the system for exemptions has developed in a piecemeal way and that medical exemption criteria is outdated, having remained largely unchanged since 1968
- Draws on Prescription Charges Coalition research and individual experiences, which show that many people with long-term conditions are not collecting their medication or are rationing it because of the cost and are experiencing worse health and, in some cases, hospitalisation as a result
- Concludes that any review of prescription charges needs to take account of the potential costs and consequences of the policy and not only what may be raised by charges.

To support the campaign work of the Prescription Charges Coalition, please visit http://www.prescriptionchargescoalition.org.uk/, and spread the word through your networks as well as participating in campaign actions.

2014 Thanksgiving Service

By Iyamide Thomas, Regional Care Advisor

'Come back to South London next year and you will get even more people'. That was one attendee's view in 2013 when for the first time ever, the Sickle Cell Society held its Thanksgiving and Remembrance Service in South London. Well, we did go back to, New Cross, South London in 2014 but whether we got more people than that inaugural 'crossing of the river' (from our usual venue in Brent) is debatable! On 22 June 2014, Reverend Canon Owen Beament welcomed the Society and guests to All Saints Church once again. The theme for 2014 was 'removing the stigma from sickle cell' and for the second consecutive year our guest preacher Christian Parker gave a pertinent and enjoyable sermon. Our special guests included actress Golda John who has entertained many of us as the grandmother in the sickle cell film 'The Family Legacy', Lucreta LaPierre MBE our longstanding volunteer who read her poem 'Storms of Life' and Victor D'Arcy-Smith who sang Handel's Messiah. After what many described as an enjoyable and informative service, guests networked and were treated to light refreshments.

Our next Church Service will be on June 21st, to commemorate World Sickle Cell Day. It will be held at St Mark's Church, Kennington at 3pm. See you there!

IN MEMORIAM

Rest in Peace My Beautiful Son.
Zane Gbangbola 2006 to 2014

Last February Nicole and I lost our Beautiful and much loved son Zane.

The tragic incident was international news and has resulted in a campaign for truth, justice, and the protection of others at risk of the consequences of flooding and Landfill see www.truthaboutzane.com No family should have to experience what we have gone through.

Zane was a remarkable, bright, and fun boy who loved god and people. Zane was loved by many and Hundreds came to his funeral.

His mum and I miss Zane every moment of the day.

One 85 year old man said 'I was struck by how compassionate (your pain in my heart) Zane was. He was the most compassionate person I have ever met' Zane loved people.

Nicole and I were heartened by the response of the Sickle Cell community, staff, Board and public who have responded with love, care, and support. We would like to thank you for your many cards, letters of condolences and prayers which brought us some comfort at what was and remains a very difficult time.

These few words could never adequately express the depth of appreciation and gratitude to all of you.

We thank you sincerely and ask that God bless you all.

I will always be glad and honoured to tell you about the love and magic Zane brought to us. Let history and us honour him with truth.

Kye Gbangbola MBA FCIOB CIHCM EurBE GDA
MIEMA CEnv LCSAP

Chair of the Sickle Cell Society

Dr Ade Olujhongobe

The news of Dr Olujhongbe's passing was a great shock to the Sickle Cell Community nearly 2 years ago. In his memory the Society has set up an award that recognises the development of new and ongoing multidisciplinary team based good practice in the treatment and care of people with Sickle Cell Disorder.

Known to his friends as Ade or Bayo he was a Medical Advisor to the Society who himself suffered from SCD. He chose not only to become a Doctor but to devote his life to combating and containing the disease. He became one of the worlds foremost experts in the field of Haematology and the related field of Oncology.

One of his most notable achiements was his leadership and championship of the development of the first ever Standard for the Clinical Care of Adults with Sickle Cell Disease launched in 2008. This outstanding work was acknowledged by the then Prime Minister of the UK Gordon Brown.

Jean Griffiths MBE

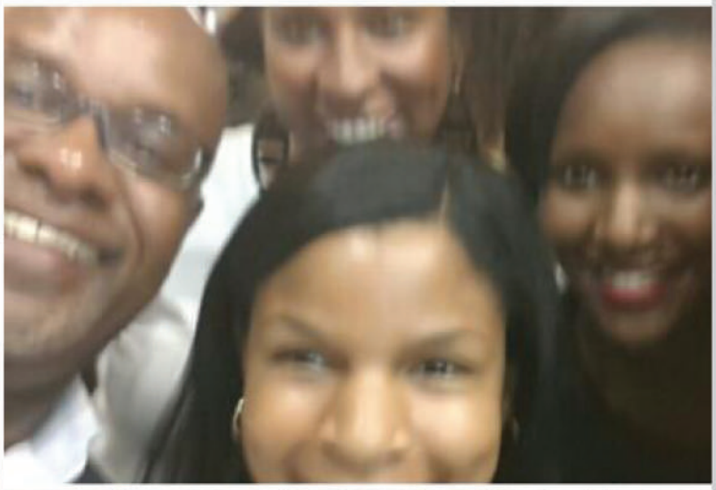
Jean Griffiths, specialist nurse and later director of the Sickle Cell Association of Grenada, sadly passed away in February 2015. Mrs Griffiths had a long career spanning more than 3 decades providing the best care to people living with sickle cell in the UK and Grenada. Mrs Griffiths was honoured for her contributions by the Queen in 2012 and 2014. She will be missed.

Errol Stanislaus

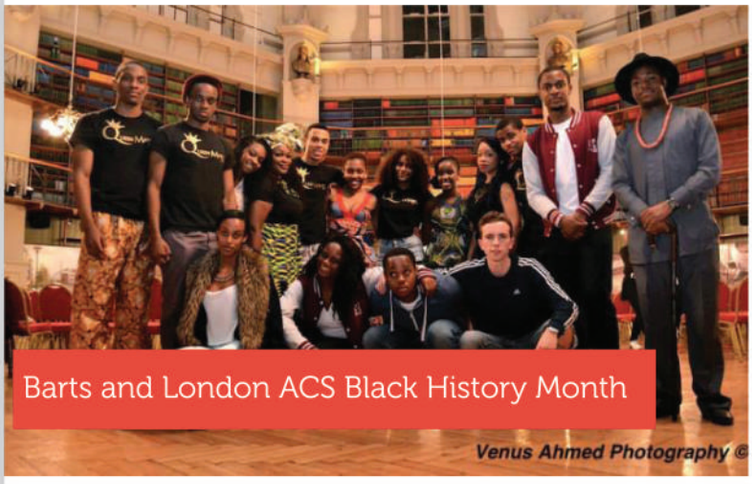
Errol was a volunteer at the Ealing, Hammersmith and Fulham support group. He was a committed and engaging member of the group, and was much loved by the members. He passed away in June 2014. His comforting words live on in the hearts and memories of the group and everyone his life touched.

FUNDRAISING UPDATE

Hariat Orimoloye's Cook Out Event



Selfie at the Hairology Conference!



Barts and London ACS Black History Month

Venus Ahmed Photography ©

British London 10K run

RBS- International Women's Day 2014

A huge thank you to our donors. These are donations over £200 we have received since April 2014

Payroll Giving 49,081	49,081	C O Sule	400
Online Giving - inclused Ex. Fundaraising	40,715	Odell Lewis	400
Mayor of Brent	8,652	Daniel Robinson & Sons Ltd	395
Prudential Services Ltd	5,000	Sylvia Parker - In memory of Ermine Jackson-Miles	365
Atonye Allagoa - Wallers	3,000	JK Group INC TF Thomson Reuters	330
Lucreta LaPierre - Ex Fundraising	2,756	Ealing Hammersmith & West London College - Christina Morris	312
Grand United Order of Oddfellows Friendly - Society Neil Robinson	1,447	AXA IM LTD	300
Overseas Fellship of Nigerian Christn	1,400	Give a Car Limited - Chinedu Nwokoro	288
Asda Collection	1,135	Trinity United Church	284
Making A Difference Locally	1,006	H E Ward (£255) & J Yogendran (£27)	282
Edgar - Ex Fundraising	1,000	obine Adoh	270
Olumuyiwa Obileye - NUGA GOLF	1,000	Church Service Collection	262
East London Mental Health Trust	878	H Smith Kiron	250
A I Adegoke - Little Essex Cookout (Facebook) Group	739	John Tower Rose Croix - Chapter Number	549,250
O F Brown	700	Onyemara Nwanney IMO/ABIA - Womens ASS London	250
Sarah Henton	628	Great Midlands Fun Run	250
Jennifer Henry	600	The Redeemed Christian Church of God	250
MITS UFJ SEC INT	500	Celestial Church of Christ - Elephant & Castle Parish	250
Caribbean Islands Association Portsmouth	500	Professional African & Asian Women Organisation	250
GFK NOP 50TH Fund - Jane Pack	500	The Parish of Saint Michael the Archangle - Gloria Walters	250
Argos Limited	500	Jerry Anderson	228
St John's & St Peter's Ladywood	490	St James' Catholic Church - C Umunna	223
David Haynes	408	HMP Humber	208
Priory Methodist Church - P Barlow	404	East Thames Group Ltd	204

The KPMG team

Lucreta and Kalpna collecting at Cambridge United Football Club

SICKLE CELL EXPERT REWARDED

Simon Dyson, Professor of Applied Sociology, Director of the Unit for the Social Study of Thalassaemia and Sickle Cell at De Montfort University, and scientific advisor to the Sickle Cell Society has received a further award. De Monfort University have conferred the prestigious 'Doctor of Science' award. This higher doctorate is awarded only in recognition of distinctive, original and sustained contribution which also advances the field. In Professor Dyson's case, the field is Social Studies in Sickle Cell.

We offer our warmest congratulations to Professor Dyson in this recognition of his work.

NEW CHAIR FOR THE ADVISORY GROUP

Following the departure of the hon Reverend John Sentamu Archbishop of York, the National Sickle Cell and Thalassaemia Advisory Group have appointed a new chair. We welcome Glenda Augustine in her new position.

Glenda Augustine has served an illustrious career in the field of haemoglobinopathies and has already contributed greatly in the field of sickle cell and thalassaemia, having led screening programmes for over a decade. Originally a clinical nurse, Ms Augustine eventually rose to manage England's first day centre for sickle cell and thalassaemia patients.

We wish Ms Augustine all the best in her new role and look forward to working with her in the future.

NEW GUIDE FOR SCHOOLS

A new law (Section 100 of the Children and Families Act 2014) places a duty on schools and academies to make arrangements for supporting pupils with medical conditions. Research has shown that schools struggle to support young people with sickle cell, but the Sickle Cell Society can offer help and advice. Working with university researchers our advisors have overseen the development of a Guide to School Policy for Sickle Cell.

'Teachers are faced with many different possible medical conditions and it is not reasonable to expect them to remember details of all of them. At the same time young people with sickle cell dislike initiatives that draw attention to them as different from their peers,' said Professor Simon Dyson of De Montfort University, who led the team of researchers. 'What was needed was a policy that supported the student with sickle cell but which operated in the background without overloading teachers with information'.

The Guide can be downloaded through our website. Get in touch with your child's school to find out if they are using it!

Superhero Run winners Rebecca, Peace, Abhesia and Elizabeth

Satnam Sokhal, completed the Run to the Beat Half Marathon

Nutrition in sickle cell—underused and underrecognised

By Claudine Matthews, Social Care Liaison Officer, Sickle Cell and Thalassaemia Centre, Homerton Hospital.

Who would have known that my 'chance' meeting with Sickle Cell Disease (SCD) would culminate in so many opportunities to change the course of my professional career?

As a Dietitian, my knowledge of SCD was non-existent; I was a blank canvas and my appointment as the social liaison officer, a service innovation to improve the social care outcomes for the sickle cell and thalassemia patients in my Trust, proved to be the catalyst for change.

My enquiry into the condition with its fascinating patho-physiology and intriguing epidemiology clarified my understanding of the condition and reinforced by my knowledge of the intertwining relationship which exists between the wider determinants of health - and its often paralysing effect on the self-efficacy of the patient and their family, poor housing, poor personal welfare and childcare for mothers with sickle cell, being major contributors.

But what about nutrition? Is there a role for Dietitians to step up and take responsibility using their expert knowledge of food and the science of nutrition and physiology to positively impact the health outcomes of this patient population?

My numerous observations identified a paucity of information on this topic, substantiated by the absence of any mention what so ever of SCD or even haemoglobinopathy in our Dietitians handbook, Manual of Nutrition and Dietetics. Something had to change!

As this field requires a wide range of collaborative working ranging from Dietitians, Haematologists, government policymakers and influences and the patients themselves; being a Dietitian, starting the enquiry with the Dietitians seemed the most logical approach.

Lack of knowledge provided the driving force for this first-line strategy aimed at raising awareness and fuelling the knowledge base of sickle cell amongst Dietitians, this led to me penning my article titled; Sickle Cell Disease: on the rise but under-recognised, challenging Dietitians to consider SCD as a long term condition, which it rightfully is and reflecting on the role the could/should play in improving the nutritional management of the SCD patient population.

Thankfully the article was accepted for publication in the December issue of the Dietitians professional magazine (Dietetics Today); the article made the front cover and was the feature article of the edition. This proved to be a 'giant step' forward for SCD in increasing awareness of the condition and possibly dialogue for change and improvement to its role alongside the clinical management of the condition.

Two recent review articles by American researchers Hyacinth et al (2010 and 2013) identified undernutrition as a critical feature for SCD and conclude that taking a nutritional approach with SCD has the possibility of increasing patient outcomes, improved Quality of Life (QOL) and future prospects. This is the challenge I've accepted and with support and more research hope to influence policy and change makers to increase the 'recognition' of nutritional intervention as being a viable treatment option for all SCD patients.

Every long journey starts with the first step and I believe my article to the Dietitians is just that and over time would feature in all policies and standards of care related to the comprehensive management of the condition aiming to improve the health and wellbeing, self-management and independence of the clients.

The article concludes that SCD is a long term condition and challenges Dietitians to reflect on and consider the role they could play in improving the nutritional management of this patient group. SCD deserves a fresh review among Dietitians. The recognition of under-nutrition as a critical feature of SCD calls for the support and expertise of a qualified Dietitian. Dietitians are well placed to make valuable contributions to research and patient outcomes and Dieticians in both acute and community settings are hereby challenged to take a fresh look at SCD as a long term condition.

PROJECTS UPDATE

'THE YORK PROJECTS'

The Sickle Cell Society represents a good voluntary sector partner investigator in potential research and recently collaborated with University of York on two research projects which reported in 2014. These were:
1) 'Involving fathers in ante-natal screening for sickle cell disorders: improving informed decision making' and 2) 'Living with sickle cell or beta thalassaemia trait: implications for identity and social life'. The Society helped to recruit individuals for interviews and focus groups and Society staff were also part of the projects advisory group. To download summaries of the research findings go to:

http://www.york.ac.uk/healthsciences/research/public-health/projects/involving-fathers/#tab-3

http://www.york.ac.uk/healthsciences/research/public-health/projects/beta-thalass/#tab-3

Brent Sickle Cell Advice and Support Service.

The Sickle Cell Society has been pleased to have been involved in several collaborations with Brent Council over past years. We are excited to be able to announce our latest venture which is supported by Brent Clinical Commissioning Group (CCG) and is the first of its kind, i.e. BRENT SICKLE CELL ADVICE & SUPPORT SERVICE.

This will be a new service benefitting Brent residents with Sickle Cell disorders, providing them with help and practical support during the initial period just after discharge from a hospital admission and also continuing to provide advice and support to help prevent future admissions.

The service will be delivered by setting up networks between specialist clinical haematology staff working in NW London hospitals, local Social Care Services, local Primary Care Practitioners and the Sickle Cell Society.

In summary, the objectives of this new service are:

- To reduce A&E attendance and hospital admissions
- To enable patients with Sickle Cell (SC) to better manage their own care and treatment
- To enable patients with SC to become more confident and informed health
- service users
- To improve primary and community care awareness of the needs of SC patients

The service will launch in June 2015

Peer to peer support in Hackney

We will be working with Hackney Clinical Commissioning Group to provide a new service in Hackney. Sheriden Russell, the lead on the project says:

'As the Peer Support and Development Officer, I am partially working in response to a health watch survey, aiming to meet health orientated requests of the community. I am also working to increase the capacity and organisation of the peer support group so they too can support their community and address their illness related needs. The Hackney Project has been set to help further support and engage members of the Sickle Cell and Thalassaemia community in the local area.'

World Sickle Cell Day 2014

Last year, we celebrated World Sickle Cell Day at Brent Civic Centre, with Dawn Butler as our Chair. The event was special for another reason - it was our 35th Birthday!

The Sickle Cell Society is going digital!

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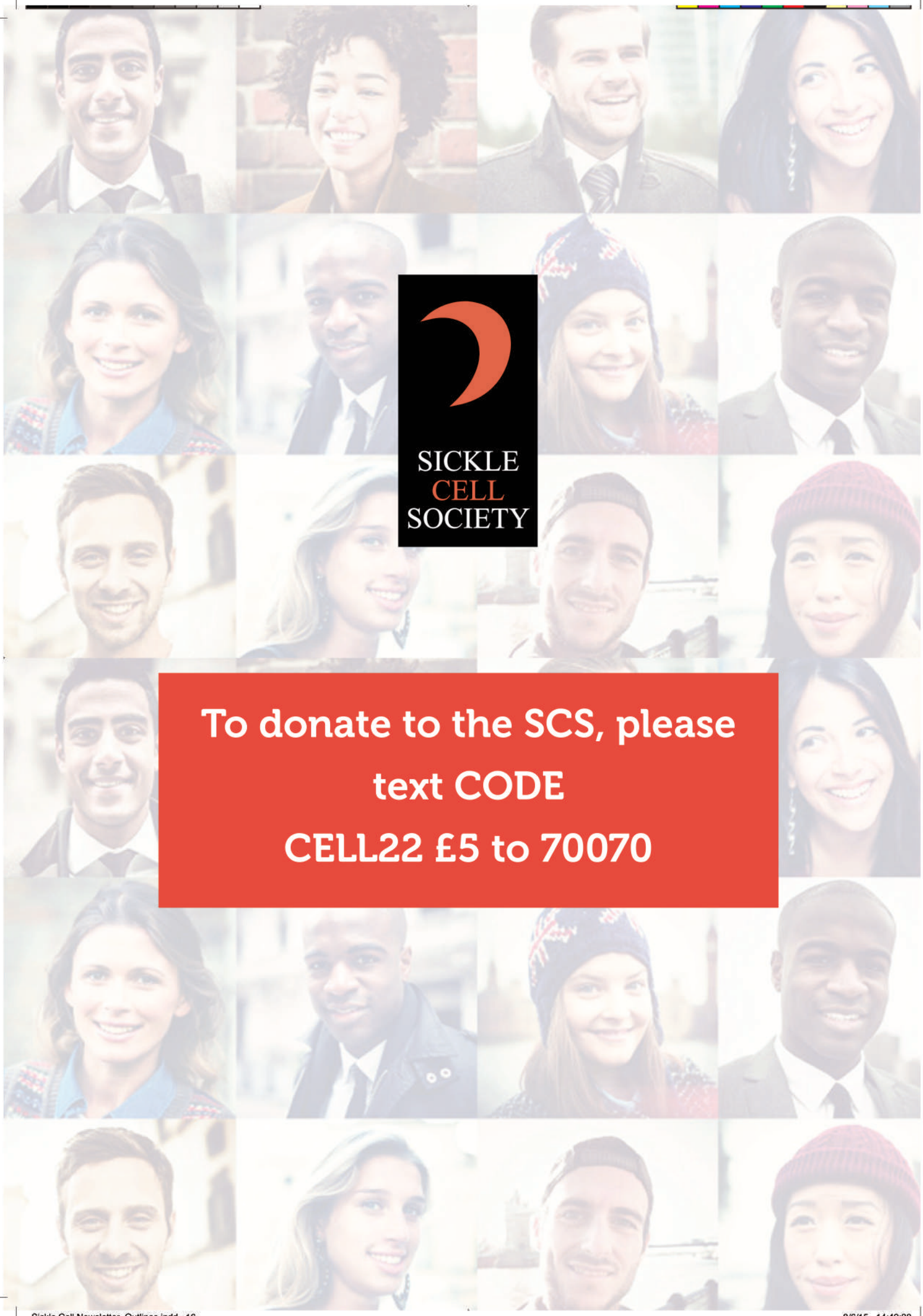
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