



Sickle Cell Society Newsletter Summer 2017



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future of sickle cell**

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service**

**Why Sickle Cell?
Professor Dame
Elizabeth Anionwu
explains**

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A welcome from the Chair

Welcome to the Spring/Summer 2017 newsletter, and a very happy World Sickle Cell Day to you. The Society have been busy over the last few months with a whole host of exciting events and activities.

Long-term patron and founding member of the Sickle Cell Society, Professor Dame Elizabeth Anionwu, was knighted in this year's New Year's Honours. In January, the Society gathered in Parliament to celebrate her contributions to sickle cell nursing. Professor Dame Anionwu read from her memoirs "Mixed Blessings from a Cambridge Union" and was honoured by Diane Abbott MP.

This event set the tone for a successful start to 2017. Throughout the year, we've hosted a series of children's activities, from pizza making to zorbing, which has helped children living with sickle cell disorder to smile. We've also taken part in engagement with NHS England, to direct what can improve services for sickle cell disorder.

In financial news, we have ended the financial year with a surplus—a phenomenal achievement. This is largely down to the hard work from the Society team and the trustees. Our fundraisers and donors also played a huge role in making this happen, and you can read all about some of the challenges they have taken for sickle cell disorder.

Sadly, this year saw the end of our successful Brent Sickle Cell Advice and Support Service. While an independent evaluation showed how this service has helped patients stay out of hospital, and there was high satisfaction, Brent Clinical Commissioning Group decided not to continue funding the service. However, we continue to provide a helpline service, which is now open five days a week, as well as our other services.

There is hope on the horizon for sickle cell, which we learned about at our most recent Patient Education Day in May. The topic, "Clinical Trials for Sickle Cell" highlighted developments in treatment, such as new drug, and a potential cure in the form of gene therapy.

And we're hopeful that this year will continue on its positive trend, with our children's holiday coming up in August, as well as further events. So sit back and enjoy our latest newsletter!

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Launching Sickle Cell South London Link



Our Sickle Cell South London Link service brings together South London's sickle cell community. We launched the service at an event in the heart of the area: Lewisham Hospital. At the launch, there was a performance from the most famous choir in South London, perhaps even the most famous choir in Britain... The Lewisham and Greenwich NHS Choir were 2015's Christmas Number One with their song A Bridge Over You. We're hugely grateful for their support, and their beautiful performance!

Learn more about the service and how to get involved at our website www.sicklecellsociety.org

New Hackney Engagement Project

We are excited to announce that we have been given funding by the London Borough of Hackney to run an engagement project with people with sickle cell living in the borough. Activities will include things like Tai Chi, massage and information sessions and will take place around the borough. The project will be managed by our Project Officer, Blaire Barrett. If you are interested in hearing more, please make sure to follow the society on social media or send us an e-mail and we'll make sure to pass on more information. We are also running a new mentoring scheme for young people in the borough. If you know of a young person who would like a mentor and who lives in Hackney please let us know.

NHS England Sickle Cell and Thalassaemia Review

NHS England are responsible for planning and buying specialised services for people living with sickle cell anaemia, thalassaemia and other rare anaemias.

As numbers of people living with these conditions continue to rise, including those living in suburban areas, further from our larger hospitals, NHS England are reviewing whether services are currently provided in the right place and enable access to the highly specialised treatments that can be required. At the heart of the review is understanding how services are working for people, so in April NHS England met with a group of people through the Sickle Cell Society and Thalassaemia UK to hear experiences and views about the current state of specialised haemoglobinopathy services and understand what works well and where people feel improvements could be made.

If there was a key theme it was how much people's experiences of healthcare services varied across the country – with some people describing their care as excellent, and others reporting poor or patchy care. Where some people felt they could quickly and easily access services as required, including psychological support, others reported barriers to getting the care they needed. Managing crises was highlighted as a particular problem. Some people struggled to get adequate pain relief, possibly due to limited awareness of the condition amongst healthcare workers, especially in urgent care. There's also an acknowledged issue with a lack of specialist staff, where some staff have retired or moved on, some clinics are struggling to recruit new consultants.



Brent Sickle Cell Advice and Support Service Closes its Doors

Sadly, our successful Brent Sickle Cell Advice and Support Service will no longer be funded by Brent Clinical Commissioning Group. An independent evaluation last year found strong positive feedback for the service, and a reduction of hospitalisations among sickle cell patients. Unfortunately, the CCG took the decision to stop funding the service, and we could not find alternative sources of funding.

The Society's headquarters in Willesden Junction remain open. People living with sickle cell in the Brent area are still able to receive information, advice and support from the Sickle Cell Society by calling us up and speaking to one of our helpline advisers. We will continue to support the sickle cell community in Brent and the rest of the UK, but we are sad that the BSCASS has been decommissioned.

CHILDREN'S ACTIVITIES

Over the past few months we have been running a regular programme of exciting children's activities for young people affected by sickle cell who live in London and the surrounding area. Kids have enjoyed a whole host of adventures including Drumming, Climbing, Zorb Ball and even a very busy trip to Kidzania!

These activities are totally free for children to attend, giving kids a chance to meet other kids with sickle cell, boost their confidence and learn new skills.

This activity programme has been supported by BBC Children in Need and, thanks to their support, we are excited to be able to continue offering children's activities for the foreseeable future.

Are you interested in your child attending some of our free activities? For more information please contact our Children's Activities Leader, Jessica Boatright – Jessica.boatright@sicklecellsociety.org or give us a call.

We are also looking for volunteers to join the fabulous activities volunteers team – please contact Jessica if you are interested.



Go Karting in South London



Kidzania May 2017



CHILDREN'S HOLIDAY 2017

From the 19th-26th August 2017 we are going to be taking a group of 30 eight to fifteen year olds and a strong team of 19 volunteers to PGL Liddington for the annual Sickle Cell Society Children's Holiday.

The children are looking forward to taking part in loads of energetic activities such as climbing, abseiling and quad biking along with sessions on healthy eating, relaxation and how to manage their sickle cell.

The holiday is currently oversubscribed but please do e-mail Jessica Boatright if you would like to join the mailing list to be the first to hear next year. Donate to the Children's Holiday 2017 www.sicklecellsociety.org/donate-to-the-childrens-holiday



WHY SICKLE CELL? Reflections from Professor Dame Elizabeth Anionwu



A generous donation from Professor Dame Elizabeth Anionwu

Sickle Cell Society patron and founding member Professor Dame Elizabeth Anionwu was knighted in the New Years Honours list for her services to nursing. Last year, she published her memoir, *Mixed Blessings From A Cambridge Union*, which we reported on in our last newsletter.

In January this year, we held an event in Parliament to honour Professor Dame Elizabeth Anionwu. Throughout her career she has been a dedicated advocate for sickle cell disorder and has been instrumental in improving services. She was knighted for her services to nursing.



The event, *Why Sickle Cell? An Audience With Professor Dame Elizabeth Anionwu*, consisted of a reading from Elizabeth's memoir, a conversation between Elizabeth and SCS president Michael Parker, a tribute from Diane Abbott MP, and a discussion with the audience.

If you would like to read *Mixed Blessings From A Cambridge Union*, it can be purchased on Amazon.



Above: Professor Dame Elizabeth at her investiture

Left: Diane Abbott MP pays tribute

Sickle Cell Society meets Association of Guyanese Nurses and Allied Professionals

The Brent Sickle Cell and Thalassaemia Centre supports the Association of Guyanese Nurses and Allied Professionals (AGNAP) in their efforts to establish a specialist sickle cell and thalassaemia screening, medical and support service in Guyana. Dr Shereyn Stanton was on a twelve week placement based primarily at North West London Healthcare NHS Trust, having secured funding from the Commonwealth Fellowship to support training a medical doctor and two nurses in the UK.

On 1st March 2017, the Sickle Cell Society hosted Dr Stanton at our office to introduce her to our work. Also in attendance were members of AGNAP, including Betty Why, Maureen Emeberi, Maria Downer, Brenda Octave and Sid Hamilton. John James (CEO) started off the morning by providing an overview of the Sickle Cell Society and the national SCD picture. Sharon Jackson and Shahnaz Qizilbash explained the work of the Brent Sickle Cell Advice and Support Service, and their direct work with patients and families. Nikki Georgiou provided an overview of the helpline

services for the sickle cell community, and some of the health and social care issues individuals living with sickle cell face. Donna Prendergast and Valeria Oldfield introduced the Sickle Cell South London Link, funded by the Big Lottery Fund. Finally, Iyamide Thomas spoke about her work for the NHS Sickle Cell and Thalassaemia Screening Programme.

We wish Dr Stanton and AGNAP all the best in their efforts to develop services for individuals with sickle cell living in Guyana.



Pan European Consensus Conference on Newborn Screening for Haemoglobinopathies – Berlin 29-30 April 2017



Top-right: Professor Dame Elizabeth Anionwu, Cathy Coppinger, and Dr Lola Oni present a poster detailing findings from the first 10 years of the NHS Sickle Cell and Thalassaemia Screening Programme. Bottom-right: John James meets Cecilia Anim, the new President of the Royal College of Nursing at the RCN's centenary.



CLINICAL TRIALS AND THE FUTURE OF SICKLE CELL

On 6th May, our first patient education day of the year took place. The theme was “Clinical Trials and the Future of Sickle Cell”

As you might already know, the future of sickle cell treatment looks more hopeful than ever. At our education day, we heard about some of the new developments on the horizon.

Our first talk was from Professor Emma Morris of University College Hospital, one of Britain’s leading experts in bone marrow transplants. Bone marrow transplants are the only cure for sickle cell disorder. The stem cells within bone marrow make red blood cells, so if a sickle cell patient’s bone marrow is replaced with bone marrow from a healthy donor, their body will start making healthy red blood cells. While this procedure offers a complete cure for sickle cell, it’s not suitable for many patients. It’s a dangerous procedure with a chance of death, and it’s only done on children who have someone who is a matched donor. The requirement for a donor is a particular hurdle, as a lot of patients do not have someone who is a match.

Professor Emma Morris told the seminar about a procedure in France, where gene therapy was used to modify a patient’s bone marrow so it did not produce sickle cells. This modified bone marrow was then transplanted into the patient, so he can produce healthy red blood cells. This procedure is currently

being tested, and may offer hope to sickle cell patients in future.

Before lunch, we split off into tables, and Dr Sophia Skyers of the Basil Skyers Foundation led a workshop with everyone present, exploring barriers to participating in clinical trials, and what might help patients and carers more likely to participate. Patients and carers had mixed views of clinical trials, with fears of the unknown and harm present; but on the other hand, understanding that a trial contributes to their own and others’ quality of life.

Patients and carers said they’d be more likely to participate in a trial if it was a “last resort”, or if it wasn’t very invasive. Fitting into their lives was another thing which patients and carers said would make them more likely to get involved, as well as a sense of altruism, and financial inducement. The following things were suggested by the groups as things that would help them get involved:

- Interactive educational days and workshops such as the one organised by the Sickle Cell Society where people can discuss issues and ask questions.
- Case studies involving black patients who have had both positive and negative experiences of clinical trials who ‘look like me’. Other participants said that they would want to hear the experiences of both black and white patients.

- Podcasts on clinical trials with case studies of different experiences
- Hearing from consultants about clinical trials and from pharmaceutical companies

Fortunately, the rest of our education day was already scheduled to include some of the suggestions from the group!

The afternoon session saw a screening of our short film, Hope for Sickle Cell, produced by Revscreen. This film allowed sickle cell patient Tinu Williamson-Taylor to tell her story about participating in a clinical trial of a new drug called GBT440, which helps red blood cells hold on to oxygen and travel through blood vessels easier. In the film, Tinu and her doctor, Dr Paul Telfer, talk about the trial, and how it not only helps patients like Tinu, but other patients in the future. You can watch the film at our website www.sicklecellsociety.org

Dr Telfer himself was in Amsterdam during the trial, but kindly Skyped in to give a short talk with more details about the next phase of the trial for this drug, and provide further information.

Our final speaker of the day was Dr Rachel Kesse-Adu of Guy’s and St Thomas’s, who spoke about how clinical trials work. It begins with testing new drugs in test tubes and animals, followed by healthy human volunteers. When researchers are sure that a drug is safe, it is tested in patients, to see how they respond to it, and whether it helps their symptoms. If it seems to work, there is a large-scale trial, where some patients receive the medicine, while others receive a placebo (sugar pill) to see how well it works. Trials are very safe, and every precaution is used to make sure patient welfare is looked after.

At the end of the day, the majority of people who attended said they’d be more likely to participate in a clinical trial! There is a lot on the horizon in the future of sickle cell treatment, and clinical trial participation could help you and others...

The Kavele Kerr-Campbell memorial garden



The ‘Kavele Kerr-Campbell Memorial Garden was opened at Leopold Gwenneth Rickus Primary School on Monday 8th May 2017.

Kavele Kerr-Campbell is the son of Simone Kerr, a valued volunteer for the Society. Kavele was 6 years old when he passed away in October 2015. He had been a student at Leopold Gwenneth Rickus since his Reception year. Kavele left us very suddenly when he was taken ill overnight and passed away as a result of complications related to sickle cell disorder.

Leopold Primary School PTFA charity with the support of the Society has been fundraising towards the cost of creating a peace garden in memory of Kavele. The garden is a reflective, quiet space that will be used as a counselling area for the students and will be located at the school’s Gwenneth Rickus site. Further funding will go towards hosting a Sickle Cell event for World Sickle Cell Day 2017 in the school’s new dining hall for all children in Brent with Sickle cell and their families.

Speakers at the event included: John James CEO, Dawn Butler MP, Prof. Dame Elizabeth Anionwu, Jenica Leigh (Children’s author), Mrs. Kendall (Headteacher) & Teachers of Kavele. There were two Choir’s that wowed us with their voices and there was ribbon cutting with a balloon release. As it stands the justgiving page set up by Simone and Leopold PTFA has raised a staggering £2,780. Kavele will always be in our hearts and we thank Simone for her endeavours.

Each Teach One

'Each One Teach One' is a small group of friends and family, that has raised funds to help young people to achieve and succeed to the best of their ability in education.

With the combined efforts and help from staff at the Sickle Cell Society, we set up an Education Support Fund that aimed to enhance and support the education of young people living with a sickle cell disorder.

After reviewing a number of applications, the two chosen beneficiaries for this fund was Deborah Omoyele, a student at Bedfordshire University studying health and social care, and Yoma Natufe, a 14 year old secondary school student from Manchester. Both Deborah and Yoma received laptops to support their studies.

On receiving the laptops, Deborah stated that having sickle cell has caused complications with her education in the past. Receiving the laptop has greatly helped her ability to complete her work, as her last one was too heavy to transport to university and kept on breaking.

Yoma was very pleased receive his laptop and Dr. Andrew Will his Consultant Paediatric Haematologist at Royal Manchester Children's Hospital said that this would go a long way to helping Yoma in his future endeavours.

Thank you to Lionel Mcguire, Roger & Jeremy Fletcher and the Each One Teach One family for providing such generous gifts.

Right: Deborah Omoyele showing off her prize and joy! Above: Presentation at Royal Manchester Children's Hospital. Craig Lloyd (Fundraising Officer) Tracey Bloodworth (Specialist Sister In Children's Haematology Department) & Dr. Andrew Will (Consultant Paediatric Haematologist)



Volunteer Story from Sheila Akinsala

Here is a story from one of our children's activities volunteers:

'I began volunteering at the SCS because I have experienced firsthand how sickle cell can affect families and some of the difficulties the illness can cause. I was keen to get involved with an organisation which made a direct impact in the sickle cell community and helped & supported those affected.

Even though I play a very small part, I feel blessed to be able to play that part, and I applaud the SCS and the work that they do. Through my involvement, I have been able to meet new people, learn more about sickle cell, get involved in children's activities and share my experiences. In all honesty, even though my aim was to give back to the community, I found that I have received so much more in return. It's been so rewarding and I've been reminded that we are all in this together.' If you would be interested in volunteering with us too - please email us using the contact details below. We'd love to hear from you!



New Regional Care Centre Opens in Birmingham

In 2015, the Sickle Cell Society, UK Thalassaemia Society and All Party Parliamentary Group on Sickle Cell and Thalassaemia hosted an event drawing attention to how adults in the West Midlands region must travel all the way to London to receive some treatments. We're delighted to report that a year and a half on, we are seeing positive changes. Sandwell and West Birmingham Hospitals NHS Trust (SWBH), in collaboration with NHS Blood and Transplant (NHSBT) and the West Midlands Specialist Commissioners, has officially launched the regional specialist centre for haemoglobinopathy, meaning that patients do not have to travel to London to receive pioneering treatment for blood conditions.

Patients attending this new centre receive automated red cell exchange treatment - a complete blood transfusion - thanks to this state of the art NHS service. This procedure removes all of the patients abnormally shaped red blood cells and replaces them with donated blood, using a technique called apheresis. Patients have received more than 500 units of blood from NHSBT since the service started. We're delighted to see that people in the West Midlands will no longer have lengthy travels for their treatment!

Society Supports Application for Stem Cell Trial

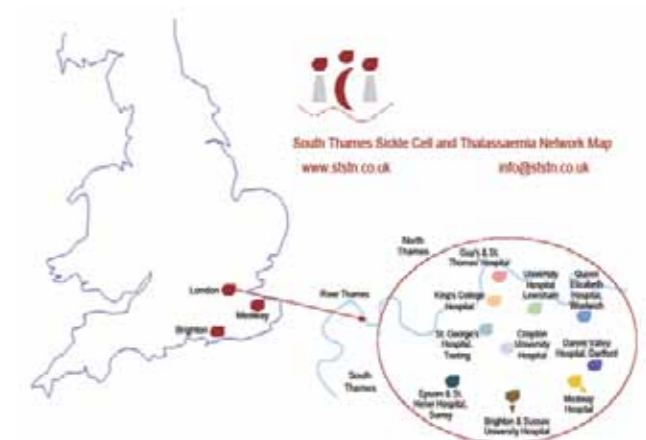
A collaborative application for a clinical trial of extending stem cell transplants to adults has been submitted to the National Institute for Health Research. The Society has written in support of this bid. We hope to see further trials in the future to open up the possibility of a cure for sickle cell to more patients.

SICKLE CELL SOUTH LONDON LINK PROJECT

The Sickle Cell South London Link Project is funded by the Big Lottery Fund and delivered by the Sickle Cell Society.

The Service offers;

- A range of resources to enable individuals to manage their condition confidently & effectively enabling individuals to maintain a healthy & active lifestyle
- Various FREE activities & family days out for children, teenagers & adults living with SCD & their families
- Assistance to existing support groups as well as establishing new peer support groups across Lambeth, Lewisham & Southwark
- Support & self-advocacy skills to improve access to services such as Health, Education & employment
- Offers topical Information Workshops held throughout the year
- Volunteering opportunities to individuals living with SCD to assist with project activities & peer support groups
- This project is open to anyone living in Lambeth, Lewisham, Southwark or attending a Specialist Sickle Cell Service in the South Thames Sickle Cell & Thalassaemia network below



FUNDRAISING SPOTLIGHT

Remissa runs the Marathon De Paris 2017

A big thank you to Remissa Bennett for completing the Schneider Electric Marathon De Paris 2017 on Sunday 9th April 2017 in 3 hours and 50 minutes and raised £536.53!



Great Freehold Bake Off!

Freehold Managers PLC organised a bake off on 17th May 2017 which raised just under £100. The white cake with the houses on won the best presentation prize and the chocolate 'castle' won the tasting contest.

Lindsey Seabrook, Office and HR Manager said 'It was great fun and everyone got really involved!'



Godfrey's Golf Day

Godfrey and the DHL Weekend PM Operations team hosted a Charity Golf Day & Dinner event. They decided to hold the function on 16th November 2016 at Heathrow Hilton Hotel.

Godfrey said:

"It is simple why I am supporting the Sickle Cell Society. I and my wife are Zambian. My wife has sickle cell and therefore I am familiar with what it is like for someone to live with sickle cell, the support that they require and the hardship that people with sickle cell go through."

Godfrey and his team donated £940.00 to the Society! Thanks for your fundraising endeavours and also to DHL for providing match funding!



Carmen's Carnival Fun

Carmen Driouch and friends organised a carnival event to raise awareness of sickle cell disorder for the deaf community.

She said "I have noticed that many black deaf people are not aware of SCD or understand how serious it is because of lack of communication skills. Terms such as Anaemia, Pain Crisis, swelling, were not known to them. So I decided to help raise awareness and funds for SCS and set up in Notting Hill Carnival Splash. I sold tickets including free meals, beer, wines, soft drinks, homemade cupcakes, cakes and raffle tickets. My friend Inigo offered us free DJ Music, and did a fantastic job playing music soca, rock, reggae & RnB. Everyone was dancing and joining in, it was fantastic!"

We are happy to support the Sickle Cell Society and appreciate the work they do, that's why we will be doing it all over again at a further event in the summer, so please come along and help us make a difference!"

Thank you Carmen and Friends for raising £320, it means a lot!



Taking a trip to the South Coast

Carey Johnson works at the Sickle Cell & Thalassaemia Centre in East Ham. Carey says 'as a Specialist Sickle Cell and Thalassaemia nurse I see firsthand the amazing work of the Society'. Therefore she is taking on the South Coast Challenge from 26th to 27th August 2017 to raise money for us. Specialist nurses already do incredible work for people living with sickle cell and taking on this challenge shows just how committed she is to the cause so please donate to help her reach her fundraising goal <https://www.justgiving.com/fundraising/carey-johnson1>.

Birmingham 10K

Thanks to Melrose Stewart for running the Birmingham 10K on Sunday 30th April 2017. Congratulations to Mel who did so well with a Finish Time: 00:52:46 and Split times: 5k Time 00:26:06. Mel raised a whopping £505.00 for us which is amazing thank you!



3 Peaks Challenge

Sarah Nelson and Friends took on the 3 Peaks Challenge, which participants attempt to climb the highest mountains of England, Scotland and Wales within 24 hours. They were walking in memory of a truly special man Robert Sasu-Twum, a true inspiration to everyone who had the pleasure to know and meet him. Robert will forever be remembered.



They did it and raised £472. Thanks so much to Sarah Nelson, Emily Gimblett, Rachel Snowden, Martin Snowden, Paula Sladdin, Tracey Wood, Esther Fowler, Andrew Howard and Helen Davidson.



Take Me Out!

University of London's ACS hosted a TV inspired 'Take Me Out' Event on Friday 2nd December, in which giving 4 lucky girls and 4 lucky guys had the chance to find bae! It was a night of laughs and love that won't be forgot for a while! Ire Soleye, LSESU ACS President was integral in setting up the event and chose to support the Society by donating all proceeds to us, which amounted to £870. Thanks Ire and everyone at University of London ACS for supporting us!



Selco

To mark the opening of the new Wembley branch, Selco offered the chance for local charities and community groups to enjoy an early 2017 bonus by applying for a £1,000 donation, with three prizes awarded. The Sickle Cell Society was selected as one of the winners by a judging panel.



Rajesh Lalji, branch manager for Selco Wembley, Craig Lloyd, John James CEO, Chris Cunliffe Selco CEO

John James, chief executive of the Sickle Cell Society, said: "Selco's donation is of huge significance as it will be used as a major contribution for our annual children's holiday which allows youngsters we support to enjoy themselves and learn to live with the condition."

John James and Craig Lloyd (Fundraising Officer) attended the Cheque presentation and thanked Selco for this generous donation.



Lip Sync Battle!

Sheree Hall and the UK Karate Squad organised a lip sync battle. As well as strutting their stuff and having a great time, the the battlers raised loads of money for the Society!.



Peer 2 Peer Support

Research has shown that Peer 2 Peer Support is beneficial as it is built on shared personal experience and empathy. We are looking for individuals with Sickle Cell to get together to provide each other with peer support, including Carers, Teenagers & Adults. If that's you, please call 0203 879 9535



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
www.sicklecellsociety.org/donate

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