

SCS October E-Newsletter

Sickle Cell Society <matthew.neal@sicklecellsociety.org>

Tue 19/10/2021 10:44

To: Matthew Neal <matthew.neal@sicklecellsociety.org>

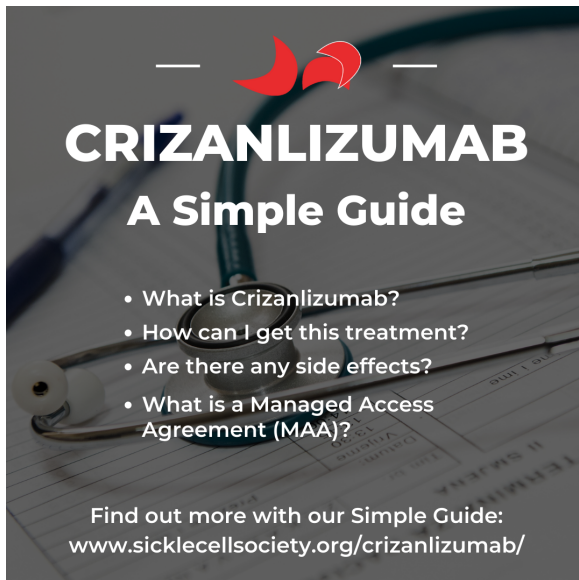


Dear Member,

We have a bumper edition of the e-newsletter this month, with more news, events and resources than ever.

We have news and updates on the new sickle cell treatment, opportunities for you to have your say and get involved, job and volunteer opportunities, news stories, personal stories, events, poetry and more.

Enjoy!



First Sickle Cell Treatment in Over 20 Years

"We welcome the new disease modifying treatment, Adakveo (crizanlizumab) and know this will be great news for people who live with sickle cell.

Sickle cell crises are extremely painful and disruptive to daily life, so it is very positive that a new treatment which can help reduce the number of crises for people living with sickle cell is being made available and funded by the NHS.

This new treatment is long overdue, being the first licensed treatment for sickle cell in the UK in nearly thirty years, which illustrates how underserved sickle cell has been over

the decades.

We hope that this will be the first of many new treatments made accessible to improve the lives of those living with sickle cell, as well as enable sickle cell patients to have a wider choice of treatments." John James OBE, Chief Executive, Sickle Cell Society.

If you want to find out more about crizanlizumab, how to get this treatment, side effects and information about the Managed Access Agreement, then check out our simple guide found at our website: www.sicklecellsociety.org/crizanlizumab/

Nurse and Medical Advisers Wanted

We're looking for a new Nurse Advisor and Medical Advisor to volunteer and join our team of sickle cell experts.

The main purpose of both roles will be to be a member of the SCS Panel of Medical and Scientific Advisers and provide up to date, high quality medical and scientific advice and professional expertise about all aspects of sickle cell disease (SCD)/Haemoglobinopathies

Help us to provide high quality medical and scientific advice and information for the sickle cell community, [click here to find out more and apply.](#)

Deadline: 25th October 2021

WANTED:
Medical and Nurse Advisors

JOIN OUR TEAM AND HELP US SUPPORT THE SICKLE CELL COMMUNITY

(Link in bio)

PAID VACANCY | PART TIME

PROJECT COORDINATOR

VIRTUAL EDUCATIONAL TOOL

Lead the creation of a virtual educational tool for boys and adults affected by sickle cell associated priapism

Find out more and apply today

Paid Vacancy: Project Coordinator (Animation Project)

We're looking for a Project Coordinator to lead the creation of a virtual educational tool for boys and adults affected by sickle cell associated priapism.

The tool will be hosted for free on the Sickle Cell Society website and will be developed working in collaboration with the UK's health professional leads in Urology and Haematology.

The Society is looking for a confident communicator, experienced in project management to ensure effective and timely collaboration with both patients and the project team across the UK and globally

(across time-zones).

They will also be responsible for timely and effective co-ordination of the project's monitoring and evaluation to enable shared learning, best practice and reporting of this innovative resource.

[Click here to find out more and apply.](#)

Deadline Friday 29th October

Join the Ascelus Service User Advisory Group

We are excited to be involved in the Ascelus research project, a new project focusing on developing and testing a new way of supporting people who have certain blood disorders to monitor their condition. The new approach will involve most patients in using a smartphone and/or a computer.

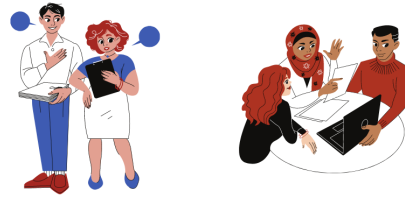
To help make sure the new approach is useful for as many people as possible, the research is aiming to set up an Advisory Group of about 4-5 people who are living with one of these blood disorders.

We want to recruit people with sickle cell from London, the South East and Yorkshire, who are not very comfortable with using online websites or smartphone apps.

Interested? [Click here to find out more](#)

**Join the Ascelus
Service User Advisory Group**

a new research project



www.sicklecellsociety.org/ascelus-service-user-advisory-group/

Have Your Say - A Message from Care Quality Commission

"At the Care Quality Commission our role is to make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

One of the most important ways we achieve this is to listen to the experiences of those people who use these services such as yourselves.

I have included a link below to the feedback page on our website. Can I ask and encourage you to help us to work with you to improve services by using the form so we can all learn and improve together."

Use the form to share an experience of care - it can be good or bad: www.cqc.org.uk/give-feedback-on-care



In Memory of Olivier Mmounda

The Sickle Cell Society were deeply saddened to hear of the recent passing away of Olivier Mmounda. Olivier lived with sickle cell and was dedicated to supporting others with sickle cell, particularly in Yorkshire and the North through the Association of Sickle Cell Sufferers of Yorkshire and Africa and Basic Information (ASYABI). Our thoughts are with his family and friends during this difficult time.

Christine Membi (The Hope Project Scotland) has kindly set up a fundraising page to help send his remains back to his family in Cameroon for his funeral. You can support it here: www.gofundme.com/f/help-send-olivier-remains-home

Statement on the Tragic Death of Sir David Amess

The APPG for Sickle Cell and Thalassaemia send our deepest condolences to the family of Sir David Amess. Sir David had been an officer of the APPG for some years and strongly supported the work we did campaigning on behalf of people living with sickle cell. It is terrible to think that once again an elected MP has been murdered doing his job, helping his constituents at a local advice surgery. We are praying for Sir David's family and are forever grateful for all he did for the APPG.

Rt Hon Pat McFadden MP (SCTAPPG Chair)
Janet Daby MP (SCTAPPG Vice Chair)



--- EVENTS ---

African Singing and Movement

Join us for some African singing and movement in celebration of Black History Month with One Drum Workshops (see their work here: www.one-drum.org/workshops)

Monday 25th October
10-11am
Ages 8-15 years
Via zoom

Sign up here: <https://forms.gle/UvMBNWusxM2xDVTn7>

Family Empowerment Workshop

Join us for a Family Empowerment Workshop

Wednesday 27th October
1pm-2pm
Ages 7-11 years

Family Empowerment Workshop includes:

- Practical ways for the family to engage in positive self-talk
- Effective strategies for the family to extend emotional vocabulary
- Practical ways for the family to improve behaviour and support children managing their feelings
- Tools to establish family members' mindset.

- A structured bank of fun and exciting activities for the family to promote and develop self-esteem, self-worth, and self-love together.

Sign up here: <https://forms.gle/p1jecbRLmGiryHea6>

Festive Performance

Do you have or live with anyone that has sickle cell who is aged 8-15 years?

If you like performing, creativity or have a performance talent that you would like to use then join us for Festive Performance.

Once a week via Zoom from Saturday 13th November until 18th December 12:30-2pm, where you will be working with Divergent Drama devising and rehearsing for a performance to show to friends and family.

Sign up here: <https://forms.gle/Jg9zjRXBtpd6C8RQ6>

Nezwick Jive Charity Night

Join us for a fun evening of dance and fundraising to celebrate Black History Month! Nezwick Jive at Anerley Town Hall presents its Black History Month Charity night in aid of the Sickle Cell Society.

Modern, soul, R&B line dance and LeRoc Jive Classes, open to beginners and no partners needed.

Thursday 28th October - 6:45-10pm

Buy tickets here: <https://nezwickjive.eventbrite.com/>

Sickle Cell and Me! By Victoria O

Sickle Cell and Me,
At war in sea,
The sea of blood you see,
You can help win the battle with me.

Sickle Cell and you,
With pain on its side too,
Struggling to keep calm through,
But there are allies that want to help you.

Sickle cell and us,
Fighting with people we can trust,
The pain is causing a fuss,
But we can get through this, all of us.

Sickle cell and me,
We had a war at sea,
We made it through the crisis you see,
Thanks for fighting the battle with me!!!

Emmanuel Amuta Poetry Award **Sickle Cell Society**

Emmanuel Amuta Poetry Award

At our AGM, we announced the winner of the Emmanuel Amuta Poetry Award. The award is for young people aged 10 -15 years who have sickle cell and are creative.

This year's winner was Victoria for her brilliant poem Sickle Cell and Me! We hope you enjoy it as much as we did.

[Click here to see the poem in a larger format.](#)

Make sure to follow us on social media to see all the other brilliant poems.

Have Your Say on How Newborn Screening Results for Sickle Cell should be Communicated

The Sickle Cell Society in partnership with the UK Thalassaemia Society and NHS Sickle Cell and Thalassaemia Screening Programme are running online focus groups with individuals to find out their views on the newborn screening programme and how they think results stating a baby is either a carrier (i.e. trait) or has sickle cell disease (or thalassaemia) should be communicated to parents.

We now want to recruit people who fall within either of the two categories:

- fathers whose babies are up to three years old and the baby's result was sickle cell / thalassaemia carrier or sickle cell /thalassaemia condition.
- people who are planning children in future and who themselves might be carriers of a gene for sickle cell or thalassaemia.



The group discussions will last up to 90 minutes and usually take place on Saturdays. Each participant will be given a gift voucher for their time.

If you would like to participate or need further information, please contact:

Iyamide Thomas (Ms), Tel: 020 7635 9328 / 07841 558611 (m) or Email: iyamide.thomas@sicklecellsociety.org

Our Voices Need to be Heard

"Trying to put the effects of sickle cell into words can be very hard but I have to find them. I have to write them, I must create awareness in anyway I can, because it's always so quiet when sickle cell is uproarious!"

In her latest Real Lives Blog, Aliya talks about how a sickle cell crisis can plunge you into darkness and the need to have sickle cell voices heard.

Read this blog and others at our website:

www.sicklecellsociety.org/our-voices-need-to-be-heard/



Reia's Story – Help in a Crisis

"For most of my life, I have been misunderstood due to my invisible illness. It is difficult for many to understand why on some days I can be happy, and on others experience such lows. This lack of awareness of what it is like to live with sickle cell is a barrier to many of us who have the condition.

Many of us dream of walking into a job, school, or any establishment without having to explain what sickle cell is, or that our condition does not obstruct our ability to succeed.



Thanks to [Eleven](#), I can monitor my own health and give back to my community while I do it - my data helps them generate better predictions, making symptoms easier to manage. Their technology has helped me massively:

I'd recently been having a sickle cell crisis for over 2 weeks but was managing it at home. As the pain grew more intense I was taking my morphine doses closer each time. I knew I had an infection that was triggering it, but the morphine masked how bad the pain really was.

I take my heart rate with Elevens' watch whenever I have a crisis, this time it gave an abnormal reading. I then checked my oxygen level: it read under 90.

I called an ambulance right away. No hesitation.

The paramedics were extremely impressed; constant use of morphine can cause respiratory failure and I was at high risk of this. If I didn't have Eleven's insights I may have been in a much worse way."

Prescription Charges Petition

Anusjka Regis-Etumnu has set up a petition to add sickle cell disorder to the prescription charge exemption list.

"We are requesting that the inherited disease Sickle Cell Anaemia, be placed on the prescription charge exemption list as soon as possible. This will contribute to a better quality of life for people who already suffer so greatly."

The Sickle Cell Society is promoting this petition as part of our work to improve the lives of people living with sickle cell,

You can sign the petition here:

petition.parliament.uk/petitions/588355



Sickle Cell Patient's 'Excruciating' Wait for Pain Drugs: BBC South East

Sickle cell patient, John Griffiths, shares his experience of being left suffering "excruciating, extreme throbbing pain" for hours on BBC South East (Thursday 23rd September 2021).

In an interview with Special Correspondent, Colin Campbell, John talks about being repeatedly left in agony at A&E after hospital staff failed to give him the medication he needs.

Colin also speaks with Kye Gbangbola, Chair of Trustees for the Sickle Cell Society, about the seriousness of a sickle cell crisis and the need for change to provide better care for sickle cell patients.



[Click here to watch the full video.](#)

That is all for the October e-newsletter. Keep an eye out for our Autumn Newsletter which will be coming out later this week.

Follow us on social media using the buttons below to be kept up-to-date on the latest news, events and resources.

If you like the work we do and are able to support us, we would deeply appreciate your donations.

We rely on your kind donations to keep doing the work we do. Every donation allows us to reach more people, run more activities, and improve the lives of those living with sickle cell.

Donate using the button below and thank you for your support!

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