SCS September E-Newsletter

Sickle Cell Society <matthew.neal@sicklecellsociety.org>
Tue 19/10/2021 10:54
To: Matthew Neal <matthew.neal@sicklecellsociety.org>

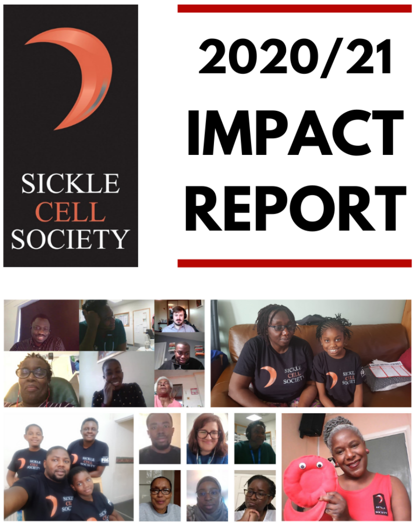
Dear Member,

We hope you and your family are keeping well.

Thank you so much to everyone who came along to our virtual AGM on the 11th. It was great to see so many of you and to have lots of engaging questions and discussion. You can find out how to watch the AGM (in case you missed it) later in this e-newsletter.

We also have our new Impact Report, ways you can get involved in our blood donation and screening projects, plus, an update on the Inquiry into Sickle Cell Care and more.

Enjoy!



Impact Report

Our Impact Report is the best way to learn about our work over the last year, with highlights from all of our projects and services.

You can also read a brief overview of our income/expenditure, to see how we spend your kind donations.

Published for our Annual General Meeting, the Impact Report is now available to download at our website: www.sicklecellsociety.org/impact21/

Inquiry into Sickle Cell Care

You may remember that back in May the All-Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG) with the Sickle Cell Society as secretariat, launched an Inquiry into Sickle Cell Care.

The inquiry aimed to examine the care sickle cell patients receive, seeking to identify why care for sickle cell patients is too often sub-standard. The inquiry was launched following on from recent high-profile examples of failings in care.

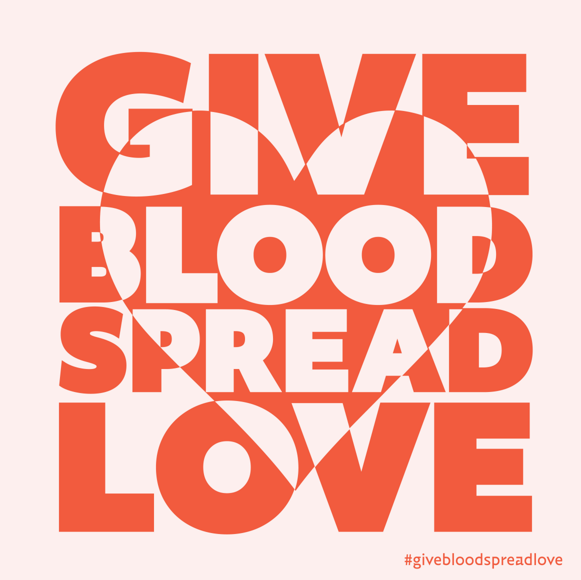
The inquiry saw written evidence from across the country, as well as oral evidence given at three virtual evidence sessions chaired by Pat McFadden MP.

The report is due to be published in October and will be shared widely amongst our members, on social media and with the press. We hope that the findings and recommendations of the report will lead to permanent, national change and ensure that the sickle cell community will not see such tragic failings again.

appg All-Party Parliamentary Group Sickle Cell and Thalassaemia

SICKLE CELL SOCIETY

Keep an eye out on our website, social media and your emails for when the inquiry report is published.



Give Blood, Spread Love, England

Work out? Feel good? Give blood

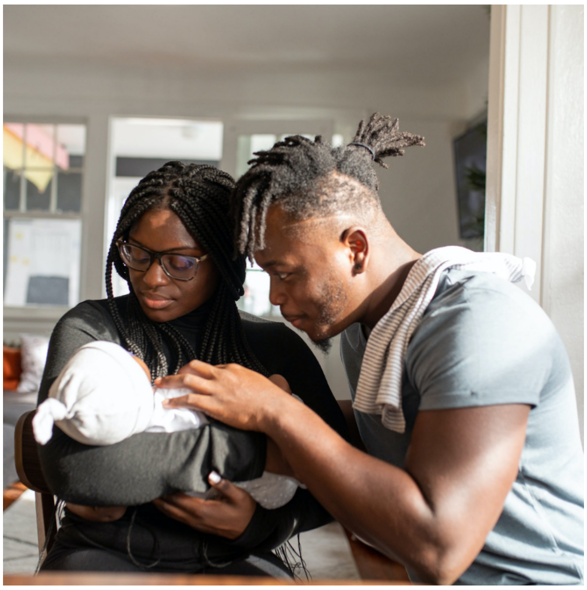
This month, as part of our Play a Part campaign, we're thrilled to be collaborating with The Gym in Lewisham, London. Our team will be hosting a fun and informative blood donor recruitment session, complete with DJ, competitions, and all the information you ever wanted about blood donation, sickle cell and the need for more black-heritage blood donors. This event is part of our work engaging with sports and active hobby groups across England where we support them to raise awareness of blood donation and sign up new blood donors. If you are part of a football team, walking group, trampolining squad, or anything similar, and want to show your commitment to improving the lives of people with sickle cell, we can work with you, too. Get in touch with us to discuss the various options. You can also sign up to save a life here: bit.ly/scsgiveblood, and follow and comment on our work at Instagram @givebloodspreadlove.

Black History Month and beyond

We are currently filling our diary with bookings to promote blood donation during Black History Month in October, and into 2022. If you are holding a large, face to face event for a black - majority audience and would like us to deliver a presentation on blood donation and sickle cell, drop us a line. We'll need to know the name of your group or event, the number of people you expect to attend and your location. (Please note we will consider if your suggestion meets our requirements and may not be able to travel to all locations.) Contact: tracy.williams@sicklecellsociety.org.uk

Join our "I Pledge.." campaign

The involvement of the black-heritage community, in all its forms, and our supporters, is at the heart of Give Blood, Spread Love, England. We are now asking you to tell us what you pledge to do to increase the numbers of black-heritage people registering to give blood. Simply send us your one-line pledge in whatever way suits you: Instagram (@givebloodspreadlove), Twitter (@givebloodlove) or email (tracy.williams@sicklecellsociety.org) Your pledge could be to “Sign up 10 male friends to the blood donation register.” (We need more male donors!) Or, if you can give blood yourself, you could pledge to “Sign up, donate blood and share my experiences to encourage others.” Don’t forget to tell us the date that you will do it by, and we’ll check in with you about your achievements and celebrate them on our social media. Drop us a line if you have any questions.



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

---

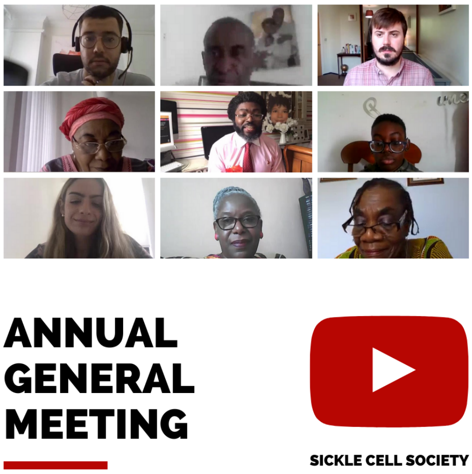
Vitamin D Research

Vitamin D deficiency is a global health issue for the black community, finds new study from the University of Surrey.

New research from the University of Surrey has recommended that people from the African-Caribbean community should consider increasing their consumption of vitamin D rich foods and taking additional vitamin D supplements, especially in the winter months.

Click here to find out more about this new research.

Always chat to your sickle cell clinician or nurse before making healthcare decisions.



Annual General Meeting

On Saturday 11th September 2021, we joined with our members and stakeholders for our 42nd Annual General Meeting (AGM).

This was our 2nd virtual AGM and saw presentations for the Chair of Trustees, Kye Gbangbola, and a finance report from President, Michael Parker FCCA, CBE.

This was followed by a Q&A session from our members about the finances and work of the Society.

After the AGM, we enjoyed the Emmanuel Amuta Poetry Award. Our NHS Engagement Lead, Iyamide Thomas, introduced the awards and we heard from this year's winner. All of the poetry entrants will be available at our website soon.

Thank you to everyone who attended, asked questions and entered the poetry competition.

Click here to watch the full AGM.

That's all for this e-newsletter. Keep an eye on our social media and your emails for our Autumn Newsletter coming soon.

You can also use the buttons below to get in touch, and to support our work with a donation.

Donate Now   Contact Us   Become a Member

Privacy Policy | Unsubscribe

Sickle Cell Society
54 Station Road, London, NW10 4UA