SCS August E-Newsletter

Sickle Cell Society <matthew.neal@sicklecellsociety.org>
Tue 24/08/2021 14:48
To: Matthew Neal <matthew.neal@sicklecellsociety.org>

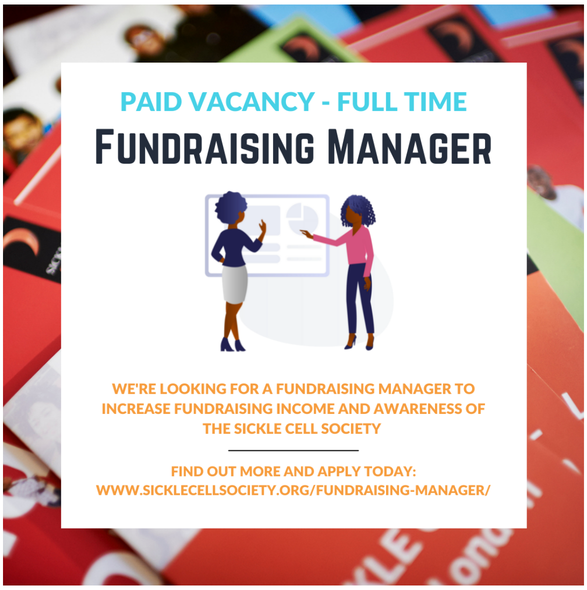
Dear Member,

We hope you are keeping well and enjoying the Summer.

In this month's e-newsletter we have a few ways for you to get involved. Including an exciting new job oppertunity, a petition for prescription charges and your chance to shape the UK Forum on Haemoglobin Disorders' Quality Standards.

Plus, read a new Real Lives blog from a brand new blogger, find out more about our Give Blood Spread Love project, and your invitation to our Annual General Meeting.

Enjoy!



PAID VACANCY - FULL TIME

FUNDRAISING MANAGER

WE'RE LOOKING FOR A FUNDRAISING MANAGER TO INCREASE FUNDRAISING INCOME AND AWARENESS OF THE SICKLE CELL SOCIETY

FIND OUT MORE AND APPLY TODAY:
WWW.SICKLECELLSOCIETY.ORG/FUNDRAISING-MANAGER/

Paid Vacancy: Fundraising Manager

We are excited to announce an exciting new job vacancy. We are looking for a full-time Fundraising Manager to take a hands-on approach to increasing fundraising income and awareness of the Sickle Cell Society.

Hours: 35 hours per week (Monday to Friday)
Salary: £32,000 – 36,000
Contract: Full-time, Permanent
Location: Sickle Cell Society, 54 Station Road, London, NW10 4UA

Find out more and apply today:
www.sicklecellsociety.org/fundraising-manager/

Annual General Meeting

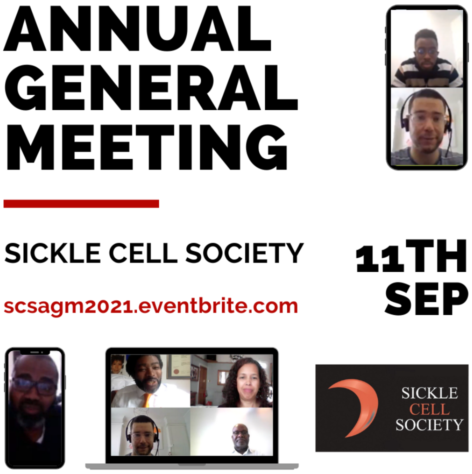
You are invited to the 42nd Annual General Meeting (AGM) of the Sickle Cell Society. In order to keep everyone safe, we will be holding our AGM virtually again this year.

We have continued to be encouraged with virtual participation from members with the recent virtual events and look forward to having you attend.

We would be delighted and honoured to have your virtual attendance at this event, details as follows:

Date: Wednesday 11th September 2021
Time: 11.00am – 1:00pm
Where: Online (via Microsoft Teams)

Find out more and register to attend here:
https://scsagm2021.eventbrite.com/



Peer Review Quality Standards - We want to hear from you!

The UK Forum on Haemoglobin Disorders is pleased to share the draft version of the Haemoglobin disorders Peer Review Quality Standards for wider consultation.

As you may know, over the last decade, the UK Forum have developed several iterations of the Quality Standards for the care of people with sickle cell disease and thalassaemia, which have set the benchmark for the quality of care provided in such disorders.

Services have developed and have been reviewed against these Standards.

They are now asking for patients, parents and carers to review the Standards and feedback any comments.

You will only need to review the Standards related to the quality and depth of patient information about various aspects of the service which can be found here.

Please send comments by 14th August 2021 using the proforma or emailing us directly to UKFHD1@gmail.com

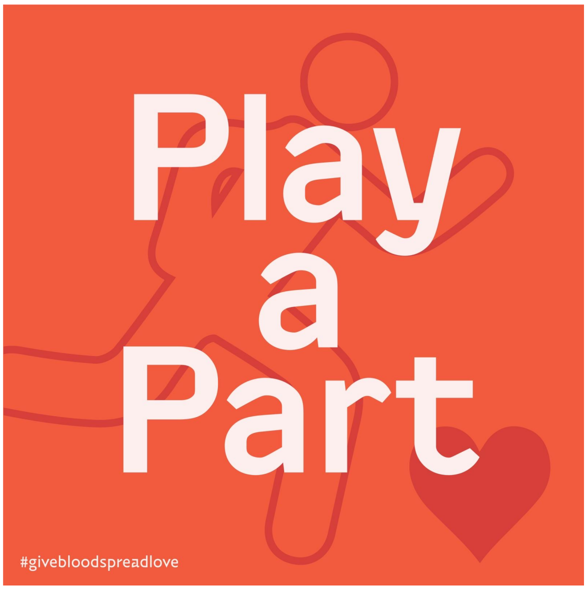
You can also learn more by watching this short video explainer by Dr Emma Drasar, Dr Rachel Kesse-Adu, Dr Farrukh Shah and Dr Subarna Chakravorty: https://vimeo.com/585245644

Give Blood, Spread Love

Give Blood, Spread Love, England launched a blood donation recruitment campaign during Sickle Cell Awareness Month in the UK which will continue to run for the next few months. The **'Play a Part'** campaign is targeting black-heritage blood donors involved in sports or active leisure pursuits. GBSLE is calling for sportspeople, organisations and fitness fanatics to get involved.

Register to give blood, ask your gym mates to join you on a group blood donation day, record a video to share on social media to encourage your friends to get involved too, or contact us to discuss other ways for you to support this campaign.

Thank you to everyone that has played their part so far including Former Premier League Footballer, Mark Bright who signed up to become a live-saving blood donor. You can join him by registering to give blood today at bit.ly/scsgiveblood and following us on Instagram @givebloodspreadlove.



Ethnically matched blood is urgently needed to support the treatment of people affected by sickle cell; we encourage all black-heritage people to give blood. Simply click on the link above, check your eligibility to give and then follow the steps to register to be a donor. People with sickle cell trait CAN donate!

Face to Face

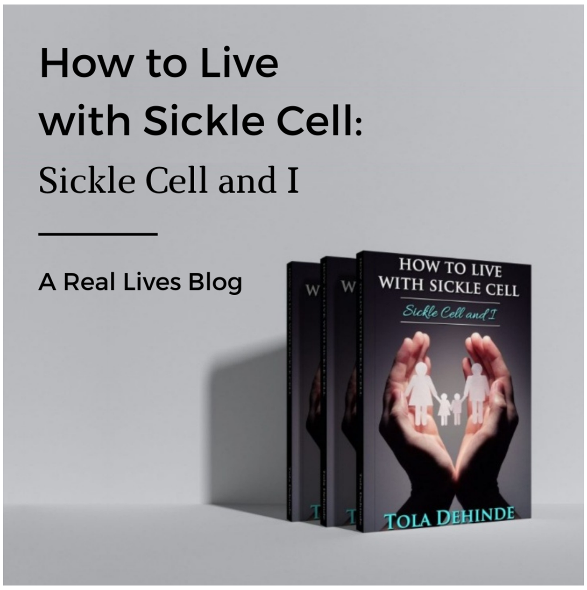
We are also seeking face to face opportunities to speak to large black -majority organisations in England about blood donation. Please get in touch with us with the name of the group, the number of people you expect to attend your meeting or event, and your location. (Please note we will consider if your suggestion meets our requirements and may not be able to travel to all locations, however we will contact you to suggest other ways you can work with us to recruit more black-heritage blood donors.)
Contact: tracy.williams@sicklecellsociety.org.uk

HOW TO LIVE WITH SICKE CELL: Sickle Cell and I

"Spending a lot of time alone and sick, reading has been a route of escape and also a solace for me."

In her first ever Real Lives blog, Tola Dehinde, talks about growing up and living with sickle cell and the power of reading and writing.

Read the full blog here:
www.sicklecellsociety.org/how-to-live-with-sickle-cell/



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

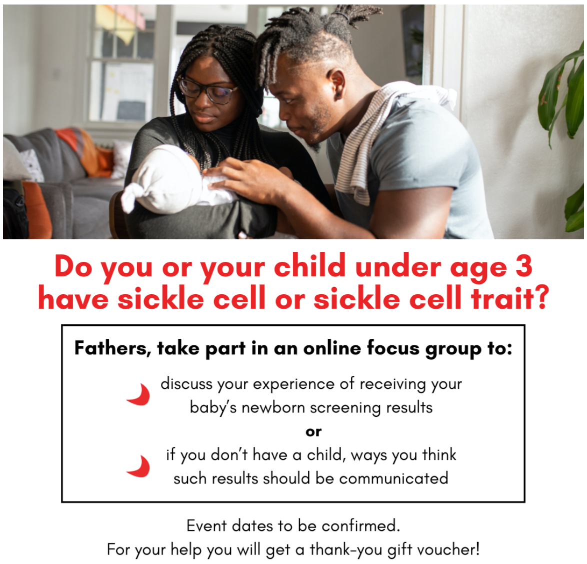
Do you or your child under age 3 have sickle cell or sickle cell trait?

Fathers, take part in an online focus group to:

- discuss your experience of receiving your baby's newborn screening results or
- if you don't have a child, ways you think such results should be communicated

Please register your interest at: iyamide.thomas@sicklecellsociety.org

For more info go to: www.sicklecellsociety.org/have-your-say-on-screening/



Do you or your child under age 3 have sickle cell or sickle cell trait?

Fathers, take part in an online focus group to:

- discuss your experience of receiving your baby's newborn screening results

or

- if you don't have a child, ways you think such results should be communicated

Event dates to be confirmed.
For your help you will get a thank-you gift voucher!

As always we love to hear from you. You can get in touch by clicking the button below. Plus, follow us on social media to be kept up-to-date on all our work.

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. If you would like to support our work, please consider donating or by setting up a fundraiser here: www.sicklecellsociety.org/fundraising/

Donate Now **Get in Touch** **Become a Member**