



June Newsletter



REFINE Study - Get Involved!

Researchers at King's College London are hoping to develop a tool that will help deliver better health and vision outcomes for people affected by inflammatory eye conditions, including sarcoidosis. They would like to better understand how these conditions and their treatments affect people in their day to day lives. They are interested in the views of patients, carers, patient advocates, and others with experience of inflammatory eye conditions.

If you would like to take part in the REFINE (**R**eporting **O**utcomes **F**or People With Inflammatory **E**ye **D**isease) study, click the button below for more information. The link will lead you to more information about what the study involves (a participant information sheet), and to an online consent form, before taking you to the online survey and/or invitation to attend an online focus group.

[Find Out More and Take Part](#)



SarcoidosisUK at WASOG 2023

Earlier this month SarcoidosisUK Senior Executive Leo attended the WASOG 2023 Conference in Stockholm. The conference focussed on the theme of "Big data - How to move the field towards precision medicine" in Interstitial Lung Diseases. The three-day scientific program was packed with lectures, exploring a wide range of topics including:

- Clinical updates and treatment options
- New concepts on disease characterisation, phenotypes, and socioeconomic determinants
- Big data, biobanks, and single-cell approaches
- Immunological approaches and methods
- Artificial intelligence applications toward Precision Medicine

Leo also had the opportunity to engage with experts and network with professionals from around the world.



Concerns Regarding Delivery of Post-exposure Treatments for COVID-19

SarcoidosisUK has joined a number of other charities in signing a letter to the Secretary of State regarding the delivery of post-exposure treatments for COVID-19. On the 27th June, the delivery of post-exposure treatments moved from the Covid Medicine Delivery Units (CMDU's) to Integrated Care Boards (ICB's). This letter addresses the uncertainty in this change and potential issues that may arise. Click the button below to read our letter.

[Read our Letter](#)



Read the June Sarcoidosis Story

For this month's Sarcoidosis Story, we're sharing the powerful journey of one of our supporters, John. He spoke with us about his experience of living with sarcoidosis and how it has affected him.

At SarcoidosisUK, we're committed to raising awareness about this disease and supporting those affected by it. If you or someone you know has been impacted by sarcoidosis, we encourage you to share your story with us. If you'd like to share your sarcoidosis story too, please get in touch with our Charity Ambassador Kemi on kemi@sarcoidosisuk.org.

We hope John's story inspires others to share their own journeys with sarcoidosis and helps to raise awareness about this disease. Click the button below to read John's story.

[Read John's Story](#)



7,000 Facebook Support Group Members

The SarcoidosisUK Facebook Groups are a welcoming and inclusive community where people affected by sarcoidosis can connect and support each other. We now have 7,000 members in our Facebook Support Group, sharing their experiences and asking questions. Thank you to all of our members for all of your contributions and for making the group such a welcoming and supportive place!

We would also like to give a big shout out to our amazing Facebook moderator volunteers, who work tirelessly to ensure our online community is safe and supportive, thank you.

[Join the SarcoidosisUK Facebook Group](#)

Thank you to our Fundraisers

SarcoidosisUK would like to say a huge thank you to all of our fundraisers! Our supporters have hosted a number of events this month, including farm days, a



Cardiff Half Marathon



1st October 2023



Cardiff

coffee and cake event, and a poker night! We are extremely grateful for your support.

We have spaces for a number of fundraising events coming up later this year, including the:

- Cardiff Half Marathon
- Yorkshire Marathon
- Run Alton Towers 10K
- and many more! For more information and events, click [here](#).

If you've been inspired to do a fundraiser of your own, get in touch with eva@sarcoidosisuk.org for fundraising support – we can't wait to hear from you!

Fundraise for SarcoidosisUK

SarcoidosisUK Upcoming Support Group Meetings

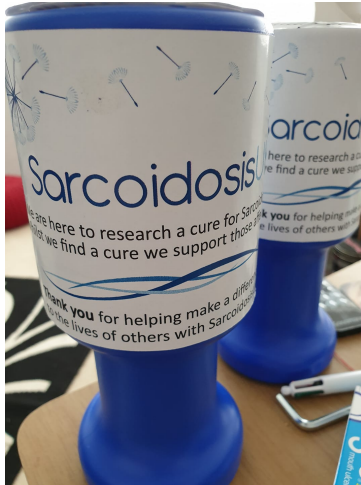


Upcoming Support Group Meetings

Please see below for the dates of our upcoming support group meetings. If you would like to attend, please get in touch with Leo on leo@sarcoidosisuk.org who will put you in touch with your local group. Anyone affected by sarcoidosis is welcome - so come along and join us!

- 18th July 7.30pm - Bristol Group Meeting
- 12th August 2pm - East Anglia Group Meeting

Find out More About our Support Groups



Support SarcoidosisUK

Please consider [donating](#) to support our work funding research into a cure and providing services to sarcoidosis patients. We need your support to continue the work we do.

Every donation will help make a difference to SarcoidosisUK and ensure that we can continue to support people affected by sarcoidosis. Make your donation by clicking the button below!

Donate

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