



October Newsletter



SarcoidosisUK's Fibrosis Research Project Update

In 2021, SarcoidosisUK and Asthma + Lung UK awarded a £120,000 research grant to Professor Ling-Pei Ho at the University of Oxford, to investigate what drives the lung scarring experienced by some patients diagnosed with sarcoidosis.

Despite a number of early challenges causing delays to the project, Professor Ho's team has made good progress on this project over recent months. 17 patients with sarcoidosis have now been recruited, which was the team's required number of participants.

Our hope is that these findings will greatly improve our understanding of the causes of fibrosis in patients with sarcoidosis; with a view to paving the way for significant progress in finding cures for the condition.

[Read the Project Update Here](#)



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 inflammatory eye conditions and their treatments affect people in their day to day lives.

The more people who participate in the study, the more robust, representative and useful the tool they develop could be to the international community of people affected by sarcoidosis!

If you would like to take part in the REFINE (**R**eporting **O**utcomes **F**or People With **I**nflammatory **E**ye Disease) study, click the link below for more information.

[Find Out More Here](#)

Saving Your Breath Petition

SIGN THIS PETITION

LET'S FIGHT FOR
LUNG HEALTH
TOGETHER



Last month, we shared the "Saving your Breath" report, published by the Taskforce for Lung Health (of which SarcoidosisUK is a member), alongside Asthma + Lung UK.

And now we need your help!

We believe people with lung conditions deserve better. That's why we are asking you to please sign the ALUK petition to tell politicians that people with lung conditions won't be ignored. The link is below, thank you.

[Sign the Petition Here!](#)



SarcoidosisUK's Research Cooperation

This month Sue Wilson, Chair of Trustees, attended a meeting of the Lung Research and Innovation Group hosted by Asthma + Lung UK. The purpose of the group is to improve lung health research and outcomes in the UK through collaboration and co-operation. The group aims to influence priority setting by government and the National Institute of Health and Care Research (NIHR). We want improved respiratory health outcomes through development of new tools and innovations, increased number of researchers, improved funding, and better healthcare infrastructure.

Sue also attended a meeting of AMRC (Association of Medical Research Charities) to learn more about their work improving collaboration among their members and putting patient involvement at the centre of any research project. There was an emphasis on smaller charities learning from other members and supporting each other to achieve research goals.

[Find Out More Here](#)



Thank You to Our Fundraisers!

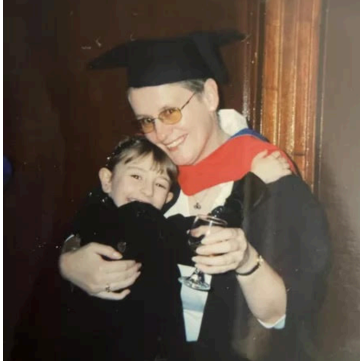
SarcoidosisUK would like to say a HUGE thank you to our exceptional fundraisers this month! Their unwavering dedication to both raising funds and spreading awareness for SarcoidosisUK is truly amazing. We've witnessed a wide array of fundraising activities throughout the month, from enthusiastic runners participating in half marathons in Cardiff, Manchester, Royal Parks, Manchester and Bournemouth, to a daredevil skydiver, as well as many other creative fundraisers. Your efforts are making such a big impact, and we're incredibly proud.

If their efforts have inspired you to embark on your fundraising journey, please don't hesitate to reach out to Eva at eva@sarcoidosisuk.org for fundraising support or check out our fundraising page below for inspiration - we can't wait to hear from you!

[Fundraise for SarcoidosisUK](#)

In Memory of Karin Bridges

We are deeply saddened by the passing of Karin Bridges, an inspirational volunteer and friend of



SarcoidosisUK.

Karin's commitment to organising the Burton Support Group brought those affected by sarcoidosis together, providing them with the support they needed. Our heartfelt condolences go out to Karin's family, friends, and everyone who had the privilege of knowing her. Her memory will forever be cherished within our community.

[Find Karin's Obituary Page Here](#)



Read the October Sarcoidosis Story

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

"In the past I have taken so many things for granted – I no longer do this." – Gwyon Jenkins

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 Gwyon's story helps to raise awareness about this disease. Click the button below to read his story.

[Read Gwyon's Story](#)



New SarcoidosisUK Support Groups

We have two new SarcoidosisUK Support Groups starting soon!

The first Sheffield Support Group meeting will be held on 16th of November at 1:30pm and is an in-person event. It is open to anyone in Sheffield and the surrounding areas.

We are also setting up a new Support Group in the North West, which will start with online meetings soon.

Like our existing groups, the aim of these new groups is to provide a place for those affected by sarcoidosis to meet others, to share their experiences, and to support and learn from each other.

If you would like to join either group, please contact info@sarcoidosisuk.org for more details!

[Find out More About our Support Groups](#)

Our Christmas Card Competition is Now Closed

Thank you to everyone who submitted an entry to our Christmas Card competition!



We received so many wonderful designs, we really appreciate the hard work everybody put in to their designs.

We will be announcing the winner on Monday, so keep an eye on our socials to see the winning design.

The 2023 Christmas card will be available on the SarcoidosisUK Shop soon.



World Mental Health Day

October 10th 2023 marked World Mental Health Day. To support this important creation, we share on our social media platforms a curated list of resources that you may find useful.

In our ongoing commitment to your well-being, we encourage you to reach out if you have any concerns about your mental health or simply need a helping hand.

You can find valuable resources about Sarcoidosis and Mental Health below, featuring tools for self-care, helpful advice for seeking additional support, and an informative Q&A video on mental health with the expertise of our dedicated nurse, Jenny. Your mental health matters, and we're here to support you every step of the way.

Sarcoidosis and Mental Health

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!

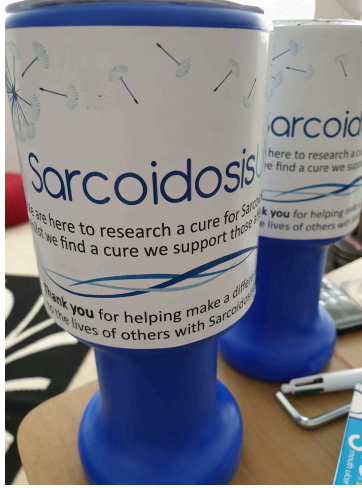
- London Group Meeting – 7th November 7pm (Virtual)
- North West Group Meeting – 15th November 6:30pm (Virtual)
- Sheffield Group Meeting – 16th November 1:30pm (In-person)
- Bristol Group Meeting – 21st November 7:30pm (Virtual)
- East Anglia Group Meeting – 2nd December 2pm (Virtual)

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

SarcoidosisUK
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www.sarcoidosisuk.org



SarcoidosisUK is a registered charity
Charity Number 1063986

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