July Newsletter

Tips for Staying Cool in the Heat

It may have taken a while to get here, but summer is now in full swing and the heat is intense!

Many people affected by sarcoidosis are more at risk of health problems such as dehydration, heat exhaustion and heatstroke. Luckily there are many ways to stay cool and lessen the impact of the heat.

"In prolonged heat waves in the summer, sarcoidosis patients have a higher tendency to have abnormally high calcium levels (hypercalcaemia). It is very important that they cover skin up, use high factor sunscreen, stay hydrated and avoid eating high calcium foods like oily fish, milk and cheese. They should go to see their GP if they experience aches and pains, vomiting, nausea and more severe than usual fatigue." - Professor Ling-Pei Ho

Find some more tips on how to stay cool this summer by clicking the button below.

Staying Cool in the Heat

So Far This Year....

300+	3,400+	34	7,800+
Nurse Helpline Calls	Information Leaflets Posted	Support Groups Held	Members in main FB Support Group

As we're sure many of you know, sarcoidosis suffers from poor quality information, low-levels of support, and almost no research into providing better outcomes for

patients. We are working hard to change this. In 2024, large numbers of sarcoidosis patients, their loved ones, and healthcare professionals have turned to us for high-quality information and free, confidential support services. We are so proud of our community and the nurses, volunteers, healthcare professionals, and donors who help us to provide this vital support.

We need your help to continue these essential services and to expand further. Please consider donating what you can so that together we can make a positive impact on the lives of those affected by sarcoidosis.

Thank you for your continued support and generosity 💙

Donate to SarcoidosisUK

Thank you to our Amazing Fundraisers!

SarcoidosisUK would like to say a huge thank you to all of our amazing June fundraisers, including:

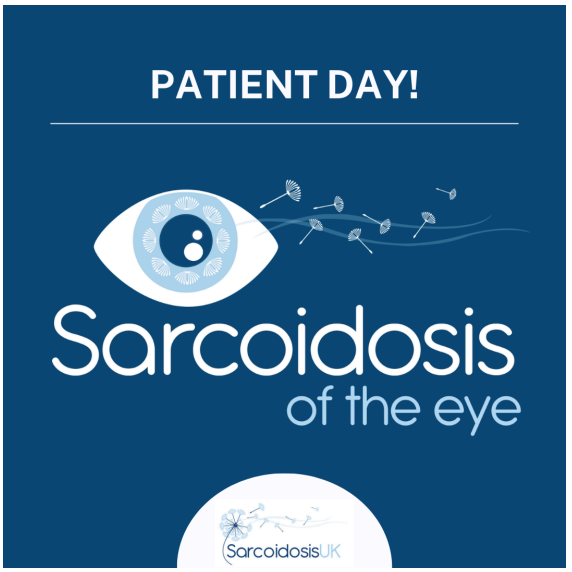
- Jean, our Sheffield Support Group Organiser, who held a rocking concert for her community in Sheffield;
- Sam who completed a staggering 7 marathons in 7 days in memory of his brother, Jason;
- Nicky who competed in a boxing match in memory of her Auntie Carolyn;
- Boston Energy (who can be seen still looking cheerful after getting stuck into the mud!) took on the Yorkshire Tough Mudder in memory of Craig Tooley;

As a small charity, fundraisers make such a big difference to the work we're able to do. Thank you!

If their fundraising has 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!

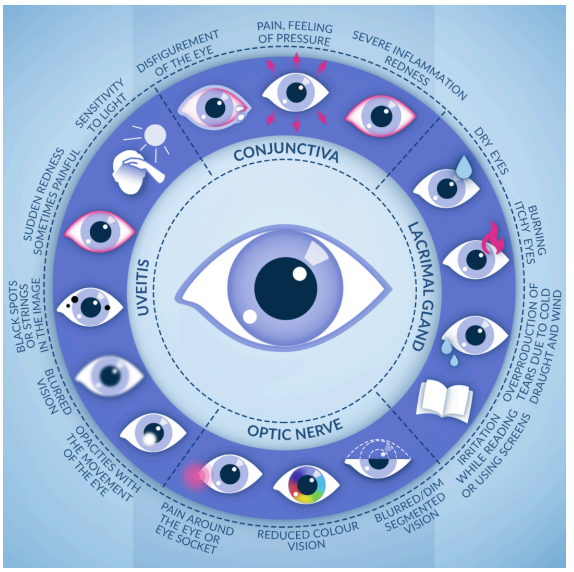
Start Your Fundraising Journey Today!

Eye problems are common in sarcoidosis. In fact, around half of all sarcoidosis patients experience eye problems. We thought it would be helpful to share some more information about how sarcoidosis can affect the eyes.



In 2022, we hosted our first ever Sarcoidosis of the Eye Patient Day. We welcomed Mark Westcott, Dr Tarunya Arun, Dr Tas Braithwaite and Professor Carlos Pavesio who gave fantastic patient-centred talks about sarcoidosis affecting the eyes.

Patient Day Videos



Ways your eyes could be affected include:

- Inflammation of the Uveal Tract (Uveitis)
- Inflammation of the Lacrimal Gland
- Inflammation of the Conjunctiva
- Optic Nerve Involvement

Sarcoidosis and the Eye Leaflet

SarcoidosisUK's Training Module for GPs

Did you know that we collaborated with the Royal College of GPs to develop a free module about sarcoidosis diagnosis and management?

Our e-Learning module is an accredited course that aims to raise awareness of sarcoidosis amongst GPs and other primary healthcare professionals, addressing common misconceptions and providing information on investigations, referral pathways, and possible complications.

This course is free for RCGP members and takes approximately 30 minutes to complete. You can encourage your GP to take the course by ordering one of our free information cards here, or sharing this link with them.

Go For Gold: Be a Champion for SarcoidosisUK

Have you been tuning into the Olympics? Are you feeling inspired? We have a HUGE number of exciting fundraising events for you to get involved in, from marathons, to 5ks, to Tough Mudder events!

Take a look at some of our featured fundraising events by clicking the button below and sign up to be one of our fundraising champions today!

Fundraising Events

Clinical Trials in Sarcoidosis

For many years there has been little interest and research into sarcoidosis by pharmaceutical companies. That is now changing! We have added a new clinical trial on our website. There are now four clinical trials specifically designed for sarcoidosis actively recruiting in the UK at the moment.

Find out more about sarcoidosis clinical trials actively recruiting in the UK by clicking the link below.

Find Out More

Check Out Our Greetings Cards!

In May, we launched two brand new greetings cards. These cards were designed by Jane Vellender, an amazing artist, and are perfect for any occasion. These cards help to spread sarcoidosis awareness among those closest to you while also supporting the charity.

Check them out on our shop website today!

Order Greetings Cards Here

Share Your Sarcoidosis Journey

Have you been reading our Sarcoidosis Stories?

Your voice is important!

Everyone has a different experience with sarcoidosis and so it is important to highlight and share as many people's journey with sarcoidosis as possible.

If you are affected by sarcoidosis, whether as a patient, a loved one, a carer, or maybe even a researcher, we want to hear your sarcoidosis story.

If you'd like to share your sarcoidosis story, please email info@sarcoidosisuk.org.

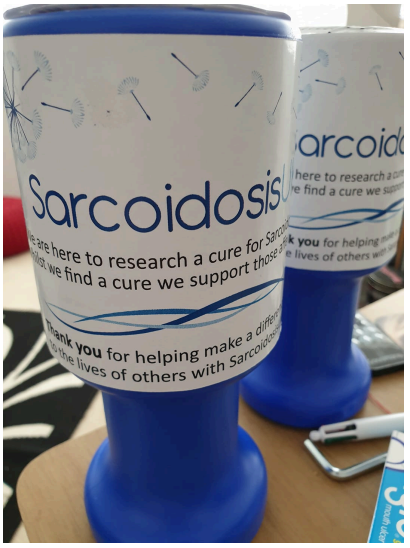
SarcoidosisUK Upcoming Support Group Meetings

Upcoming Support Group Meetings

Please see below for the dates of our upcoming support group meetings. If you would like to attend, please email info@sarcoidosisuk.org. Anyone affected by sarcoidosis is welcome - so come along and join us!

- London Group Meeting (Virtual) - 5th August 7:00pm
- North West Group Meeting - 12th August 6:00pm (Virtual)
- Scotland (Edinburgh) Group Meeting - 7th September 2pm (In-person)
- Bristol Group Meeting - 17th September 7:30pm (Virtual)
- Scotland (Glasgow) Group Meeting - 7th October 6pm (In-person)
- Bristol Group Meeting - 17th October 7:30pm (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
214 China Works, 100 Black Prince Road, London, SE1 7SJ
info@sarcoidosisuk.org
www.sarcoidosisuk.org
SarcoidosisUK is a registered charity
Charity Number 1063986