View in browser

September Newsletter

Neurosarcoidosis Patient Day 2023 - Recordings and Transcripts Now Available

On 23rd September 2023, SarcoidosisUK hosted our annual Neurosarcoidosis Patient Day. Thank you to everyone who attended this event. It was a fantastic day, and we hope you enjoyed it as much as we did!

At this year's event, we heard from four brilliant neurologists, covering these important topics relating to neurosarcoidosis:

- What Causes Sarcoidosis
- Clinical Manifestations of Neurosarcoidosis
- Management of Neurosarcoidosis
- Future Developments

If you missed any of the talks, or would like to watch them again, the recordings and transcripts for each session are now available on our Patient Day Hub.

Visit the SarcoidosisUK Patient Day Hub

Thank You to Our Fundraisers!

SarcoidosisUK would like to say a HUGE thank you to our amazing fundraisers this month! They have all worked so hard to raise both money and awareness for SarcoidosisUK, and we couldn't be prouder.

- Paul and Alex Dawson held the 'Julie Dawson Memorial Match' at Izaak Walton Fisheries raising £1013
- Derek completed the South Coast Ultra Challenge raising £1030!
- Hannah completed the Scottish Half Marathon, raising £635
- Justin continues his journey to the Rome (and Edinburgh!) Marathon, completing the London Big Half
- The annual Tour de Lyme cycle took place this month, raising £1,518
- The Pharmacy MADE team have been moving for a collective total of 1,000 miles over September for SarcoidosisUK

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

Read the September Sarcoidosis Story

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

"I am very proud of our NHS service and the consultants who provided me with such great care and gave me a second chance at life" – Anton O'Hara

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

Read Anton's Story

New SarcoidosisUK Support Group in the North West

We are hoping to set up a new SarcoidosisUK Support Group in the North West!

Like our existing groups, the aim of this new group 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 be informed about when the first meeting will take place, please email leo@sarcoidosisuk.org to confirm that you would like to be added to the mailing list.

The NHS Guidance for the Shingles Vaccine has Changed

From September 2023, anyone who is severely immunosuppressed and over 50 will be offered two doses of a non-live vaccine called Shingrix.

If you are in any doubt about this vaccine, please consult your GP or consultant.

Click the button below to read the new advice from the NHS.

Read the New NHS Avice Here

World Lung Day

25th September 2023 marked World Lung Day. In about 90% of patients, sarcoidosis affects the lungs and/or lymph glands. This is known as 'Pulmonary Sarcoidosis'.

To see common symptoms of pulmonary sarcoidosis and techniques to understand the condition, please visit our website here.

We will continue to work hard so that we can help to support those affected by sarcoidosis, fund research and spread awareness. Please consider making a donation through the link below. Any amount will help make a difference and contribute to our vital work. Thank you!

Donate to SarcoidosisUK Here

SarcoidosisUK attends ERS Congress 2023

Earlier this month, Leo Casimo, Senior Executive at SarcoidosisUK attended ERS Congress 2023 in Milan, Italy.

ERS Congress is the world's largest respiratory meeting, with over 20,000 delegates in attendance this year. The Congress featured a wide range of sessions on all aspects of respiratory medicine, from basic science to clinical practice.

"ERS Congress 2023 was a valuable opportunity to learn about the latest advances in respiratory medicine and to network with other professionals in the field. My time at Congress was not just about gaining knowledge, but also strengthening bonds within the sarcoidosis community. One of my highlights was meeting with the ELF Sarcoidosis Patient Advisory Group in-person for the first time, after years of connecting virtually. It was great to get together and discuss priorities for people with sarcoidosis and how to raise awareness in the coming year".

Unlocking Better Lung Health: 'Saving Your Breath' Report Highlights

The Taskforce for Lung Health (of which SarcoidosisUK is a member), alongside Asthma + Lung UK published a new report "Saving your Breath". This report unveils eye-opening data: Lung conditions cost the UK £13.8bn, and the UK holds Europe's highest lung disease death rate. The report also includes policy recommendations that could save the NHS £307m a year, reduce hospital bed days by just over 272,000 a year, and improve the quality of life of the six million people living with a lung condition in the UK.

Let's fight for lung health, together.

Read the Full Report Here

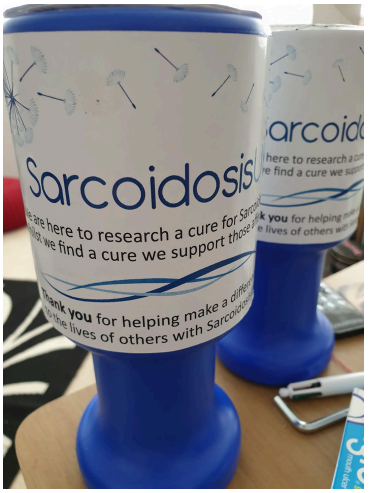
SarcoidosisUK Upcoming Support Group Meetings

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 - 2nd October 7pm (Virtual)
- Hertfordshire Group Meeting - 11th October 6:30pm (Virtual)
- East Anglia Group Meeting - 14th October 2pm (Virtual)
- Scotland (Glasgow) Group Meeting - 17th 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