April Newsletter

Sarcoidosis Awareness Month

Throughout April we celebrated Sarcoidosis Awareness Month - from our fundraising challenges to the Sarcoidosis Patient Day, video interviews and more, we spread the word about sarcoidosis and were thrilled to see so many of our supporters get involved too. Raising awareness isn't just for April though - we will continue to work hard all year round to improve the lives of people affected by sarcoidosis, and need your help to do so. If you can, please consider showing your support by making a donation to fund our work by clicking the button below.

Donate to SarcoidosisUK

Sarcoidosis Patient Day

On the 28th of April, we hosted our annual Sarcoidosis Patient Day with the Royal Brompton and Harefield Hospitals. Thank you to everyone who attended this important event. If you missed it, the recordings and transcripts will be available soon on the SarcoidosisUK Patient Days Hub, where you can also watch back all of our previous Patient Days.

In the next few days, we will be sending our Post-Event Survey to everyone who attended this year's event. Please do take the time to complete this short survey so that we can ensure that our future Patient Days are as effective as possible.

Visit our Patient Day Hub

The Future of Research for SarcoidosisUK

For the past few years SarcoidosisUK have conducted the majority of our research in partnership with the British Lung Foundation (BLF), who have doubled our research budget for each project. This has been an invaluable partnership that has allowed us to ensure greater efficiency and maximise our investment, funding projects that otherwise would not have been possible.

The BLF's research strategy has recently seen a shift in focus - having merged with AsthmaUK, the research that they will be funding going forward will centre on lung disease as a whole, rather than projects specific to rare diseases such as sarcoidosis. We will therefore no longer be funding research in partnership with the BLF.

We have however got some exciting plans for research projects that SarcoidosisUK will fund independently, and look forward to bringing you further updates later on in the year. Click the button below to read the full statement.

Read our Research Statement

The Sarcoidosis Patient Charter

SarcoidosisUK are pleased to launch our International Patient Charter along with the other members of the ELF Sarcoidosis Patient Advisory Group.

The Patient Charter outlines our joint strategy for the future improvement of patient care and quality of life for people with sarcoidosis. Our hope is that the charter's Call for Action will raise awareness and widen understanding about the impact that this condition has on many people.

We call on patients, caregivers, healthcare professionals, policy makers and the general public to support the charter and to help disseminate it as widely as possible. Click the button below to download the Patient Charter in Dutch, English, German and Spanish (coming soon in French, Italian and Serbian).

Download the Patient Charter

SarcoidosisUK on Radio Breakfast Show

In April SarcoidosisUK were welcomed onto the Voice of Islam's Radio Breakfast Show to talk about sarcoidosis as part of their World Health Day segment.

SarcoidosisUK would like to express our thanks for this opportunity to spread the word during Sarcoidosis Awareness Month! Click the button below to hear the recording.

Listen to the Recording

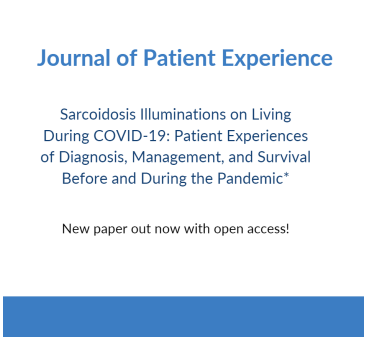
Laura's Sunrise Walk for SarcoidosisUK

SarcoidosisUK would like to say a HUGE thank you to Laura, who completed her fundraising walk up Coniston Old Man during Awareness Month!

She raised an incredible £8,645 and we are so grateful to her and everyone else who took part in the hike. Thank you Laura, you have helped to make such a big difference.

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

Fundraise for SarcoidosisUK



Sarcoidosis and COVID-19 Research Paper

A research paper relating to COVID-19 and sarcoidosis, which SarcoidosisUK made significant contributions to, is out now in the Journal of Patient Experience.

"Sarcoidosis Illuminations on Living During COVID-19: Patient Experiences of Diagnosis, Management, and Survival Before and During the Pandemic" is available to read by clicking the button below.

Download the Research Paper

Safe at Work Campaign Updates

The #SafeAtWork letter, published by KidneyCareUK and supported by SarcoidosisUK, has been updated now that we are 'Living with COVID-19' and the working safely guidance and requirement to consider COVID-19 specifically in a risk assessment has now ended.

You can download this letter by clicking the button below and use it to share with your employer to help you discuss your safety at work.

Download #SafeAtWork the Letter

Register for the Chronic Cough Patient Conference

Do you have chronic cough? Join ELF's first Chronic Cough Patient Conference to learn more about this condition. The Chronic Cough Patient Conference will take place online on Saturday 7 May, from 09:30-13:00 CEST/08:30-12:00 BST. It is being organised by members of the ELF Cough Patient Advisory Group and medical experts from NeuroCough – a European Respiratory Society (ERS) Clinical Research Collaboration (CRC). Click below to find out more and register.

Register for this Event

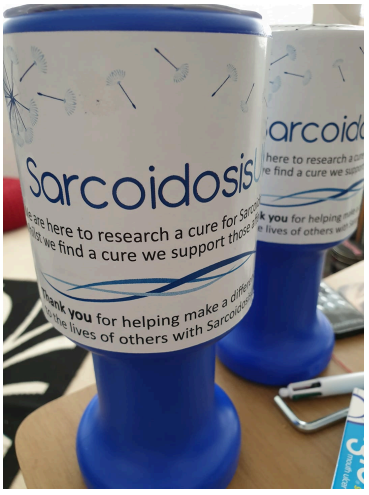
New SarcoidosisUK Video

SarcoidosisUK are extremely proud of all the work that we do to help sarcoidosis patients each and every day. If you would like to learn a bit more about what we do and meet the team, click the button below to watch our new charity video.

With your help, we'll continue to support patients, spread information, raise awareness and fund vital

research. Thank you for being a part of our journey.

Watch our new Video



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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SarcoidosisUK is a registered charity
Charity Number 1063986