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April Newsletter

This April was Sarcoidosis Awareness Month and it was a great opportunity for us to shout about sarcoidosis, the work we do, and our supporters.

Read about everything we got up to this month!

Thank you for Going Blue!

We'd like to say a HUGE thank you to everyone who chose to Go Blue for Sarcoidosis this awareness month! We have been overwhelmed by the support shown this April and all of the awareness and vital funds raised will truly make a big difference to those affected by sarcoidosis. From wearing something blue every day, to holding a gaming stream with a Dandelion Festival, to a blue bake sale, to sharing our posts and information about sarcoidosis, you've done it all! All of your efforts are making such a big impact, and we're incredibly proud 💙

Buildings Across the UK Shone a Light on Sarcoidosis!

This year we asked buildings and landmarks across the country to light up in blue to shine a light on sarcoidosis. Throughout the month, we had over 40 locations across the UK lighting up!

We are so grateful to all of the locations that joined this campaign and lit up show their support for everyone affected by sarcoidosis.

Keep an eye on our socials to see a round up of all of the gorgeous photos that were sent in during the month.

Sarcoidosis is No Joke

The start of Sarcoidosis Awareness Month fell on April Fools Day and we took this opportunity to share why sarcoidosis is not a joke.

We asked those affected by sarcoidosis what they wish would be taken more seriously. We had so many responses that touched on all aspects of sarcoidosis and daily life. They highlighted the strain of chronic fatigue; the lack of co-ordinated care during treatment; and the impact of sarcoidosis on mental health.

Read More Here

Sarcoidosis Information Videos

This awareness month, we reached out to Dr James Galloway, Dr Rakesh Sharma and the Royal Brompton Cardiac Team, and Dr Tarunya Arun to each create a short information video about how to support yourself if you have sarcoidosis. They each kindly recorded a video, touching on Sarcoidosis and Joints, Muscles and Bones, Cardiac Sarcoidosis, and Neurosarcoidosis.

Click below to watch them today!

Watch the Sarcoidosis Information Videos

New SarcoidosisUK Information Leaflets

Throughout the month we released three new information leaflets, covering:

- Sarcoidosis and Medication
- Sarcoidosis and the Endocrine System
- Sarcoidosis and Pregnancy and Fertility

All of our information leaflets are free to access to ensure sarcoidosis patients, their family and friends, and medical professionals have access to accurate and up-to-date sarcoidosis information.

We are so grateful for all the consultants who have helped in creating these information leaflets.

See All of our Information Leaflets Here

New SarcoidosisUK Support Services Poster

On World Health Day (April 7th) we launched a new SarcoidosisUK Support Services Poster!

We know that sarcoidosis can be confusing and isolating, particularly for newly diagnosed patients. Our goal is to ensure that everyone affected by sarcoidosis is aware of the free support available for them and that they're not alone.

We have sent a copy of our poster to everyone on our Consultant Directory, but why not pick up a poster today to hand in to your local clinic?

Order a Poster Here

Welcome to the team Graham!

We'd like to welcome Graham as our new Senior Executive!

Graham comes to us from the commercial world of online payments, having worked in senior roles for some major global businesses. He is excited to be joining the team at this time and is very aware of the challenges facing those with sarcoidosis as a member of his close family has the disease.

We're delighted to have him onboard!

The office team took on the Victoria line

On the 12th of April, the office team took on the length of the Victoria Tube Line, due to it's blue branding, to raise awareness of sarcoidosis as part of our Go Blue awareness month campaign! We hit all 16 stations on the line which was 15.6 miles in total and took us just under 6 hours.

The sun was out for the whole walk, showing its support for sarcoidosis which kept us going (along with some snacks along the way!)

Open Mic Sharing Night

People affected by sarcoidosis and their family and friends were invited to come along and share their creative outlet with others.

This was a great night, and we had a mixture of musical performances (from singing to trumpet playing), poems, people speaking about their sarcoidosis journey, and we even saw a picture of an amazing cake creation!

Sarcoidosis can affect people in many different ways and so it was really great to see the different forms in which people are able to express themselves. Thank you so much to everyone who shared, to those who came to support and listen, and to Kemi for organising and hosting this creative session.

You can listen to Kemi's song New Form here and check out the Mad Ferret Band here.

In other news...

Thank you to our amazing fundraisers!

SarcoidosisUK would like to say a huge thank you to the following April fundraisers;

- Amy who shaved her head and waxed men's legs, chests and backs in memory of her Dad, Paul;
- Kristen who has walked 10,000 steps every day this month;
- Our London Landmark Half runners, Sam and George, running in memory of their Dad, and Kieron, running in memory of Phil;
- Greg who completed his first half marathon at the Plymouth Half;

and more, including a London Marathon runner and a Boxing Match! As a small charity, fundraisers make such a big difference to the work we're able to do.

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!

Read the April Sarcoidosis Story

For this month's Sarcoidosis Story, we're sharing the powerful journey of Nicky. She spoke with us about her experience of living with sarcoidosis and how it has affected her.

"It has been difficult to process and accept at times that this has happened to me and that I may have it for the rest of my life. The loss of the life I had before and learning to deal with the new me has been hard and I feel my confidence and self esteem have taken a big hit. The pain, lack of

sleep and fatigue gets me down at times but I am much better than I was 6 months ago, so I'm grateful to be getting back to something a bit more normal."

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

Read Nicky's Story

Sign up to EasyFundraising

We're now registered with easyfundraising, which means you can help us for FREE. Over 7,000 brands will donate to us when you use easyfundraising to shop with them – at no extra cost to yourself! All you need to do is sign up and remember to use easyfundraising whenever you shop online. It's easy and completely FREE! These donations really mount up, so please click below to sign up and support us.

Sign up to EasyFundraising

Further clinical trial sites have begun in the UK!

For many years there has been little interest and research into sarcoidosis by pharmaceutical companies. That is now changing! New clinical trials specifically designed for sarcoidosis are taking place in the UK as well as USA and other countries. Some of the UK clinical trials have had new investigation sites added.

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

Find out more about Clinical Trials

OneVoiceILD and Action for Pulmonary Fibrosis News!

OneVoiceILD and Action for Pulmonary Fibrosis have launched a long-term vision for the future of ILD care in the form of a new optimum integrated care pathway. This report looks to tackle the current challenges to equitable and timely delivery of care. We think that their recommendations will have positive implications for those with sarcoidosis, including those affected by pulmonary fibrosis. Click below to read their report.

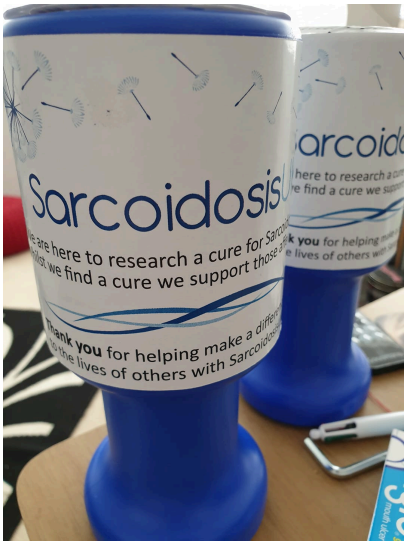
Read the ILD Care Pathway Report

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!

- Sheffield Group Meeting - 16th May 7pm (In-person)
- East Anglia Group Meeting - 18th May 1pm (In-person)
- Bristol Group Meeting - 21st May 7:30pm (Virtual)
- Scotland (Edinburgh) Group Meeting - 8th June 2pm (In-person)
- Bristol Group Meeting - 18th June 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
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SarcoidosisUK is a registered charity
Charity Number 1063986