



Email not displaying correctly?
[View it in your browser.](#)

SARCOIDOSISUK

MONTHLY NEWS

SEPTEMBER

Dear Friend of SarcoidosisUK,

This month we have a very exciting 20th Anniversary Campaign update to share with you!

I spent some time at the ERS International Congress in Paris earlier in the month. This was an excellent opportunity to meet other sarcoidosis organisations from across Europe and learn about the latest sarcoidosis developments in research and clinical practise. More details on what I got up to are below.

Finally, SarcoidosisUK have launched an online shop! You can now buy customised bags, t-shirts and more, with all donations to sarcoidosis research.

As always, please **drop us a line anytime**, it would be great to hear from you.

Best wishes,
Jack Richardson, SarcoidosisUK Executive Officer

20TH ANNIVERSARY CAMPAIGN - WE REACHED OUR £60K GOAL!

The SarcoidosisUK 20th Anniversary campaign has raised over £63,000!

Our 20th Anniversary Campaign has been celebrating the amazing work of SarcoidosisUK over the last two decades.

We had an ambitious target of £60,000 and are thrilled and very proud to have exceeded that! We could never have achieved such a remarkable amount without the help of all the amazing supporters who have been involved in the last year by donating or fundraising. You know who you are - you are all superstars!

Stay tuned for news soon on how we will be investing these funds directly into research for a cure for sarcoidosis.



20TH ANNIVERSARY CAMPAIGN

DONATE TO THE CAMPAIGN

SARCOIDOSISUK SHOP

SarcoidosisUK have launched an online charity shop!

Check out our amazing selection of customised SarcoidosisUK products including:

- Bags
- T-shirts and running vests
- Awareness ribbons and balloons
- Information leaflets

Whether you are fundraising, raising awareness or just want to look great you will be sure to find something that suits your needs perfectly!

100% of shop proceeds are doubled by our research partners and invested into research for a cure.



RAISE AWARENESS | FUND RESEARCH

VISIT THE SHOP NOW!

EUROPEAN RESPIRATORY SOCIETY CONGRESS REPORT

European Lung Foundation (ELF) Patient Advisory Committee (PAC)

Jack attended his first ELF PAC meeting in Paris. Items on the agenda included publishing clinical trials results, WHO air quality commitments and a call for patient input to the ERS RESPIRE Fellowship programme.



Patient Organisation Networking Day

Jack presented the SarcoidosisUK Nurse Helpline as an example of an 'Innovative Collaboration in Patient Education' to over 100 delegates at the Patient Organisation Networking Day.

KSQ

Jack met with top sarcoidosis specialists from the UK and USA to discuss the next steps for the King's Sarcoidosis Questionnaire online tool. Stay tuned for further updates soon.

Sarcoidosis Patient Priorities Project

A new Sarcoidosis Patient Priorities project will contain important information for sarcoidosis patients across Europe in multiple languages. Click below to see past examples of Patient Priorities website for other conditions.

Sarcoidosis Taskforces

Updates from the ERS Sarcoidosis Treatment Guideline (to which Jack is contributing as part of the Patient Advisory Board) and the American Thoracic Society Sarcoidosis Diagnosis Guideline which is due for publication later in 2019.



Above: Representatives from sarcoidosis organisations from the UK, Germany, Austria, Switzerland, Spain, Italy, Netherlands and Serbia. All will contribute to the new ELF Patient Priorities project.

[READ MORE ABOUT ERS CONGRESS HERE](#)

SUPPORT GROUPS ROUND UP

Our SarcoidosisUK Support groups are really friendly; they meet every 4 or 6 weeks in community centres, libraries and other public spaces across the UK. The groups are all run by volunteers who have sarcoidosis themselves. Upcoming meeting dates are below. Everyone is welcome so come along and join us!

October/early November 2018 meetings:

- Oct 6th ~ Cornwall and Devon Sarkies (CADS) (Plymouth)
- Oct 13th ~ Hampshire
- Oct 16th ~ Bristol
- Oct 22nd ~ North Kent
- Oct 24th ~ Leeds
- 4th Nov ~ Burton
- 5th Nov ~ Brighton
- 6th Nov ~ London
- 7th Nov ~ Northampton



"I went to my first SarcoidosisUK support group meeting and didn't know what to expect. Met some lovely people with the same struggles it was nice just being with people that understand...I certainly found the meeting beneficial and will be going to the next one, I would recommend going to a support group to anyone that hasn't yet."

SarcoidosisUK Central London Group attendee, September 2018

[MORE DETAILS AND RESERVE TICKETS](#)

SUBMIT YOUR SARCOIDOSIS PATIENT STORY

Sarcoidosis can be a lonely and isolating condition. We want to make sure that patients can share experiences and learn from each other. Each month we publish a Sarcoidosis Patient Story in this section of the Newsletter.

[DO YOU HAVE A SARCOIDOSIS PATIENT STORY TO SHARE? CLICK HERE.](#)

SarcoidosisUK relies on your support and donations! Please...

DONATE TO SARCOIDOSISUK

...to show your support and help us find a cure for sarcoidosis!

Please do get in touch anytime you would like to chat, we would love to hear from you.

**Best wishes,
SarcoidosisUK**

FOLLOW SARCOIDOSISUK:



Please get in touch, anytime, and we will get back to you:
49 Greek Street, London, W1D 4EG
020 3389 7221

info@sarcoidosisuk.org
www.sarcoidosisuk.org

SarcoidosisUK is a registered charity | Charity Number 1063986

This and past editions of the SarcoidosisUK Newsletter can be downloaded in pdf format from [our website](#).

We hope you like our newsletters. If you don't, [simply unsubscribe](#).