



[SarcoidosisUK
Survey](#)

[Neurosarcoidosis
Patient Day](#)

[Step Into
Summer
Walking
Challenge](#)

[Research
Update](#)

[SarcoidosisUK
on the BBC](#)

[Donate](#)

May Newsletter



SarcoidosisUK - Have Your Say!

SarcoidosisUK has grown significantly in recent years. As we grow, we are thinking about how we can provide the best possible service to people affected by sarcoidosis in the UK. Please complete our [survey](#) to have your say on the work we do and inform the future direction of the charity. We really value your input and we will use your responses to help SarcoidosisUK grow and improve.

[Have Your Say!](#)



Neurosarcoidosis Patient Day

On the 26th June 2021 (14.00-18.00 BST), we will be hosting our annual [Neurosarcoidosis Patient Day](#). This is a free virtual patient day, created specifically for sarcoidosis patients. The event will provide patients with quality information about neurosarcoidosis and will include engaging talks from Professor John Brewer and neurosarcoidosis expert Dr Desmond Kidd.

Dr Kidd will deliver a session about 'Neurosarcoidosis Treatment and Management' and Professor Brewer will give a talk called 'The Role of Exercise and Nutrition in the Management and Control of Sarcoidosis'. We'll also hear from Jacqui Newton and Leo Casimo, who will be hosting the patient day and talking about their experience working with SarcoidosisUK.

[Find Out More And Register](#)

Step Into Summer Walking Challenge

June is the month we've all been waiting for – summer is set to begin, and the final stage of the roadmap out of lockdown is just around the corner. It's the perfect time to get outside and enjoy a daily walk, so we're



challenging you to [#stepintosummer](#) and do 10,000 steps each day in June for SarcoidosisUK.

There's loads of ways to hit your 10,000 steps per day... from exploring your local area to taking the dog for a walk or doing a fitness class, get the challenge done doing what you love (steps from pub to pub count too!). Once you've raised £50 you'll receive a free Step Into Summer Walking Challenge t-shirt to help spread awareness!

[Sign Up and #stepintosummer](#)

**SarcoidosisUK Research Grant 2017
Interim Report**



Dr Steven Fowler

SarcoidosisUK Research Update

In 2017 we committed £60,000 to a project analysing breath samples from sarcoidosis patients to try to identify a cause.

The team involved in this research set out to collect samples of exhaled breath from patients with suspected or known sarcoidosis, to check for compounds that may be associated with lung inflammation and/or infection that could be linked to the condition. The researchers hoped that the compounds they could detect would tell us more about a number of crucial issues relating to sarcoidosis, such as: its cause; the importance of lung infection and inflammation; and whether the condition is responding to treatment.

Dr Fowler, lead researcher for the project, and the rest of his team have made fantastic progress so far and outlined next steps for the project.

We look forward to updating you in due course with a final report, which we anticipate will lay the foundations for the further development of this exciting project.

[Read the Interim Report](#)



SarcoidosisUK on the BBC!

Last month we told you about Juliet, who had been taking on her own version of the SarcoidosisUK Warrior Walk - she had been aiming, under Doctor's advice, to walk an additional 3000 metres in 30 days to raise funds for SarcoidosisUK. Not only did Juliet manage to complete her challenge - she went above and beyond, walking a total of 4100 metres in 30 days!

The BBC came to film the final moments of Juliet's challenge and also spoke to Leo Casimo, Senior Executive at SarcoidosisUK. You can watch the clip [here](#).

Juliet's efforts have been nothing short of amazing - if you'd like to show your support, please consider donating to her JustGiving page [here](#).

[Watch the Video](#)

International Nurse Day

Help support the SarcoidosisUK
Nurse Helpline in honor of
International Nurse Day



The 12th of May was International Nurse Day, which celebrated the contribution that nurses make to societies around the world. SarcoidosisUK are extremely grateful to all the nurses and frontline staff that have worked tirelessly over the past year during the COVID-19 pandemic, including Jo and Jenny, the two NHS nurses who run our [SarcoidosisUK Nurse Helpline](#).

Since we receive no government funding, we rely on your generosity to keep support services like the helpline going. If you would like to make a donation that will go towards the SarcoidosisUK Nurse Helpline, please click the button below.

Support the SarcoidosisUK Nurse Helpline



MYGIVINGCIRCLE.org

We're giving
£300,000 to
Charities!



Vote Now

For the Charities you love

Vote for SarcoidosisUK

MyGivingCircle are giving away £70,000 to 80 charities with the most votes by June 30. Anyone can nominate a charity to win one of the grants, and it's quick and easy to do. The more nominations a charity receives the greater their chance of winning!

We would really appreciate it if you could [submit a nomination for our charity](#) and ask your family and friends to do the same. The grant could make a real difference to the work we do and your vote could be the one that helps us win! You will also receive an email to validate your vote - please check your inbox and be sure to click the link in the email to make sure your vote gets counted.

Vote for SarcoidosisUK



European
Reference
Network

for rare or low prevalence
complex diseases



Network
Neuromuscular
Diseases (ERN EURO-NMD)



ERN-LUNG Registry

To find out where patients with rare respiratory diseases live and how they can be better helped, the European Reference Network for Rare Diseases of the Respiratory System (ERN-LUNG) has started a European Population Registry.

The registry will be used to improve research in rare lung diseases. As a registered user, you can enter your medical data, which can be used for different research projects, with the goal to improve healthcare and research in this area.

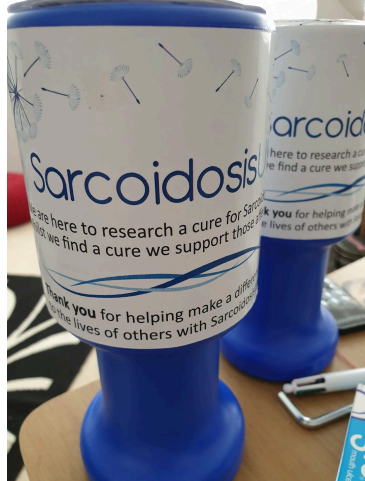
The more patients register, the more medical research can benefit. To ensure sarcoidosis patients are well represented, please consider joining the registry.

Join the ERN-LUNG Registry

Support SarcoidosisUK

Please consider [donating](#) or [becoming a member](#) 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.

Donate



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