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June Newsletter



Neurosarcoidosis Patient Day

Thank you to everyone who joined us for our [Neurosarcoidosis Patient Day](#) on the 26th June. This was a free, virtual event that provided patients with quality information about neurosarcoidosis.

We heard excellent talks from Professor John Brewer and neurosarcoidosis expert Dr Desmond Kidd. We also heard from SarcoidosisUK Patient Ambassador Jacqui Newton, who spoke about her experience working with the charity.

If you missed it, you can watch the recording of the event by clicking the button below!

[Watch the Patient Day Recording](#)



SarcoidosisUK on the Sarc Fighter Podcast

Leo Casimo, Senior Executive at SarcoidosisUK, recently spoke to John Carlin in a brand new episode of the [Sarc Fighter Podcast](#).

The podcast is for individuals whose lives are impacted by sarcoidosis and other rare or chronic illnesses, and tackles big topics from the basics of the disease, lifestyle changes, treatment options, research progress, and most importantly: the voices of those affected by the disease.

In this latest episode, Leo chats to John about the work of SarcoidosisUK and you can now listen on all major podcast streaming platforms or click the button below.

[Listen to the Podcast](#)



© R. Jack Richardson (SarcoidosisUK), Prof. David Davies, Dr. Mark Jones (both University of Southampton), Henry Bedford (SarcoidosisUK), November 2019

SarcoidosisUK 2019 Research Project Update

In 2019 we committed £60,000 to a laboratory analysis of sarcoidosis scarring in the lungs. The aim of the research is to understand new key information about the scarring process, which will inform clinical trials and may enable new treatments to be developed.

As for many researchers, the COVID-19 pandemic prevented laboratory access from March until August 2020, slowing Dr Jones' studies. However, access has now resumed and exciting progress has been made. You can read the Interim Report [here](#).

We look forward to providing more updates about this exciting research in due course!

[Read the Interim Report](#)

SarcoidosisUK Superstar Thank you Linda!



Linda Courtney's Epic Bike Ride

On Saturday 19th June Linda completed her epic 12 day bike ride from Lands End to John O'Groats in memory of her sister Davina. Covering the entire length of the UK, this route is certainly not for the faint hearted, and is truly an incredible achievement.

SarcoidosisUK cannot thank Linda enough for all that she has done to raise funds for the charity. Her JustGiving page is now at over £10,000, meaning that she has doubled her original fundraising target.

You can show your support and read Linda's story [here](#). Well done and thank you Linda, we couldn't continue our vital work without people like you.

[Support Linda's Fundraiser](#)



Connecting the Sarcoidosis Family - A Global Project for a Global Disease

For the past few months Joanne has been raising awareness of sarcoidosis on a global level, collecting photo notes from people and asking them to write the word 'sarcoidosis' along with their location. "When you're told you're chronically ill with a disease you've never even heard of, your world becomes so much smaller. This project is to show that sarcoidosis is a global issue that requires global solutions."

Joanne has managed to collect an astounding 230 different locations from all corners of the world. Each photo has its own link to a hospital, clinic or consultant that treats sarcoidosis (where one doesn't exist a hospital that treats autoimmune and/or rare diseases has been linked). Take a look at this incredible project [here](#).

[Visit the Website](#)

PIP Q&A - Reminder

PIP Q&A Video

New date: Thursday 1st July 2pm

Join us for the PIP Q&A video
with SarcoidosisUK Nurse Jenny.



The new date for our PIP Q&A video will be Thursday 1st July at 2pm.

SarcoidosisUK Nurse Jenny will be answering questions about PIP (a payment which can help you with some of the extra costs if you have a long term physical or mental health condition or disability).

Tune in on our Facebook, Twitter or YouTube channel!

[Subscribe to our YouTube Channel](#)

SarcoidosisUK Becomes a Member of the Taskforce for Lung Health

We are delighted to announce that we are now a member of the [Taskforce for Lung Health](#)!

The Taskforce was set up in 2018 to develop a five year plan to improve lung health in England. Independent of government, it is a unique collaboration between patient representatives, health care professionals and other experts with a shared vision and passion for positive change.

We will work to ensure that sarcoidosis voices are heard and incorporated into the work of the Taskforce and its 5-year plan for improving lung health in England.

[Find Out More About the Taskforce](#)

Sign up for one of our events!

Firstly, a massive thank you to everyone who took part in our Step Into Summer challenge - we are so grateful to all of our fundraisers who make our work possible!

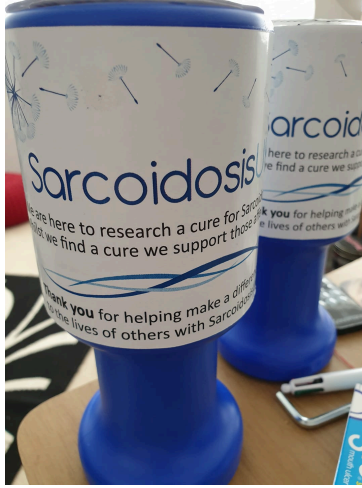
If you didn't take part or would like to do another fundraising activity for SarcoidosisUK, why not sign up for one of our upcoming summer events? Whether you'd like to challenge yourself to a 5k, 10k or half marathon run, or perhaps a sponsored swim or cycle, we have a whole range of events to choose from. Browse our events [here](#) or get in touch with Charlene, our Marketing & Fundraising Executive, at charlene@sarcoidosisuk.org to help find the right event for you!

[Take a Look at our Events](#)

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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