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September Newsletter



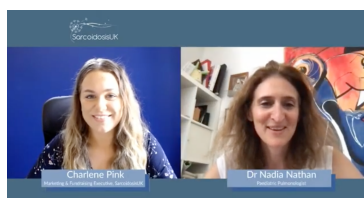
Health-Related Quality of Life in Sarcoidosis

On Friday 17th September, SarcoidosisUK Senior Executive Leo was joined by Dr Anne Marie Russell, who spoke to us about Health-Related Quality of Life (HRQoL) in sarcoidosis.

As well as answering questions from patients about health-related quality of life in sarcoidosis, Dr Russell discussed the findings from her recent research into the topic. You can read the full paper [here](#).

Click the button below to watch the Q&A!

[Watch the Q&A](#)



Sarcoidosis in Children

Sarcoidosis in children is extremely rare. The actual number of children with sarcoidosis is hard to assess due to the lack of an international systematic reporting system, but it has been estimated at approximately 0.4 to 1 per 100,000 children.

On the 8th of September, SarcoidosisUK Marketing and Fundraising Executive Charlene was joined by Dr Nadia Nathan to answer questions from patients about childhood sarcoidosis. You can read Dr Nathan's research paper into the topic [here](#) and watch our Q&A by clicking the button below.

[Watch the Q&A](#)

COVID-19 Vaccines Information

The Joint Committee for Vaccination and Immunisation (JCVI) has recommended that all people in the UK who were immunosuppressed at the time of their first or



second COVID vaccine should receive a third dose to help protect them from the virus. The aim of this is to reduce mortality, morbidity and hospitalisations from COVID-19 over the 2021 to 2022 winter period and through 2022, as well as to minimise the COVID-19 case infection rate and the chance of new variants emerging. Find out more [here](#).

In light of this the British Thoracic Society have produced helpful guidelines, FAQ's and information for the respiratory community who may be called to have a third dose. Click the button below to read this information.

We will be holding a virtual Sarcoidosis Patient Day in October centred around the topic of COVID-19 Vaccines - keep an eye on our social media for more updates on this which will be coming soon.

[Read the BTS Vaccines Information](#)

New Research Paper Published:

'A Systematic Review of Physical Activity and Physical Fitness in Sarcoidosis'



A Systematic Review of Physical Activity and Physical Fitness in Sarcoidosis

As part of our Neurosarcoidosis Patient Day back in June, Professor John Brewer gave a fantastic talk about the role of exercise and nutrition in the management and control of sarcoidosis - you can watch the full video [here](#). Professor Brewer's talk was largely based around a piece of research titled 'A Systematic Review of Physical Activity and Physical Fitness in Sarcoidosis'. This research highlights the potential benefits of fitness and physical activity for patients with sarcoidosis - you can now read the full paper by clicking the button below.

[Read the Research Paper](#)



Tour de Lyme 2021

In July 2015, James Milbourne sadly passed away suddenly after having a cardiac arrest as a result of undiagnosed Sarcoidosis. He was just 29. For the fifth year running James' family and friends cycled 144 miles on the 9th and 10th September in his memory, journeying from James' hometown Worcester to Lyme Regis where he spent many holidays with his family. SarcoidosisUK would like to say a massive thank you to everyone involved in the cycle ride - an incredible amount was once again raised for our charity and we are beyond grateful for the continued support year on year. If you'd like to show your support please click the button below.

[Support This Fundraiser](#)

Big SarcoidosisUK Walk

On 18th September SarcoidosisUK held a virtual Big Sarcoidosis Walk to raise awareness for all those affected by the disease. Thank you to all of you who took part and raised vital funds for SarcoidosisUK, we couldn't continue our work without people like you! Keep an eye on our socials for our next virtual challenge, or



Thank you to everyone who took part in our Big Sarcoidosis Walk!

take a look at our other fundraising events by clicking the button below.

[See More SarcoidosisUK Events](#)



Sign Up to the Ultra Halloween Challenge

This October Ultra Challenge is putting on a hair-raising hike around some of London's scary streets and historic haunts for Halloween! You can choose to complete a 10k, half marathon or full marathon walk on your own or gather your bravest guys & ghouls to make up a team. All the routes start & finish at the Dungeon, deep in The Oval Cricket Ground, on Saturday 30th October – with an eerie overnight option on the marathons. Find out more and sign up by clicking the button below or contact charlene@sarcoidosisuk.org for more information!

[Sign Up for the Challenge](#)



SarcoidosisUK Badges

Last year SarcoidosisUK released [badges](#) to raise awareness and help keep you safe during the COVID-19 pandemic. Now that restrictions have eased, many sarcoidosis patients still have concerns around how to protect themselves and may be anxious about mixing with others in public spaces. Our badges are still available on the SarcoidosisUK store, and can help others around you to understand your condition.

There are four versions of the badges:

- “I have an underlying condition. Please be extra careful around me.”
- “I can't wear a mask. I have a lung condition.”
- “My cough is not contagious. It's sarcoidosis not coronavirus.”
- “My cough is not contagious. I have a lung condition.”

All profits made from the sale of our badges are devoted to research into a cure and supporting the sarcoidosis community. Get yours [here](#).

[Visit the SarcoidosisUK Store](#)



International Day of Charity

On the 5th September we recognised all the great work that charities do around the world to bring about positive change. Thank you to everyone who showed their support for SarcoidosisUK on International Day of Charity by donating or signing up to fundraise for us - it means a huge amount! If you'd still like to donate you can do so [here](#) or get in touch at charlene@sarcoidosisuk.org if you want to find out more about fundraising.

[Donate](#)



Our Leeds Support Group is Looking for a New Organiser

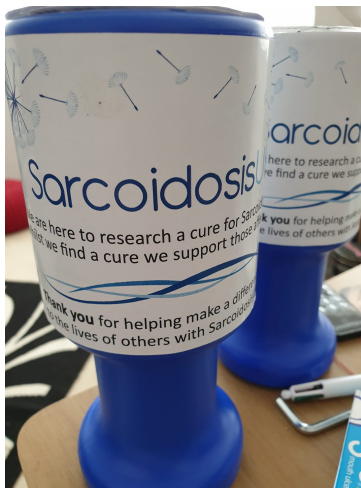
We are looking for a volunteer Support Group Organiser for our fantastic SarcoidosisUK Leeds Group. The role of Support Group Organiser is extremely rewarding and is an opportunity to make a real difference in the lives of sarcoidosis patients in your area.

Could you volunteer as the Leeds Support Group Organiser?

- Are you based in Leeds?
- Do you have personal experience of sarcoidosis?
- Do you have the skills necessary to run a support group?
- Can you give a few hours a month to help local people with sarcoidosis?

There are a range of tasks to be done, for example, organising group meetings and leading discussions but don't worry, you won't be alone! We will be there to help every step of the way. If you are interested becoming the support group organiser for the Leeds support group, please send an email to leo@sarcoidosisuk.org who will let you know more about the role.

[Find Out More About Our Support Groups](#)



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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