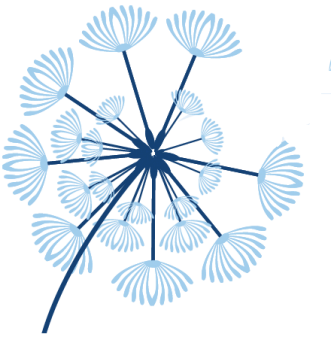
Register for the Cardiac Sarcoidosis Patient Day | Sarcoidosis and Mental Health Q&A | 2022 SarcoidosisUK Calendar | Donate

October Newsletter



The Next Steps for SarcoidosisUK

The COVID-19 pandemic has forced many charities to re-think their current structures and processes in order to ensure they remain alive, and SarcoidosisUK is no exception to this. As a result, the charity will be looking to convert from its current structure as an Unincorporated Charity to a Limited Liability Charitable Incorporated Organisation (CIO).

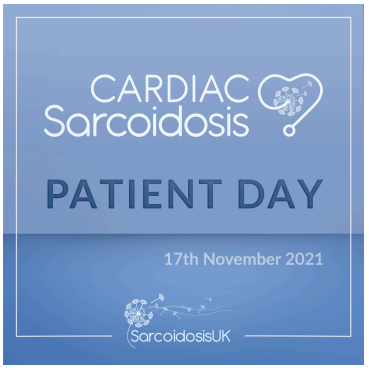
Despite the past year and a half being particularly challenging for the charity sector, SarcoidosisUK saw significant growth over this period of time as patient demand for information and support reached an all time high. Whilst the charity's growth is undoubtedly a great achievement, with it comes increased risk complexity for current members under the structure of an Unincorporated Charity. Under our current unincorporated structure, risks are not limited to SarcoidosisUK, but are borne by the members of the charity, whereas converting to a Limited Liability CIO limits the risk to the organisation.

The conversion to a Limited Liability CIO has only recently become an option for charities, yet will mitigate this risk to members and provide a much-needed step in the right direction to allow us to continue on a pathway of sustained growth.

SarcoidosisUK's current Constitution & Articles no longer suit the position we are in today, furthering the need for the transition. The CIO structure will best suit the charity's needs going forward, and SarcoidosisUK would request that members consider this when attending and voting during the next AGM (date to be announced in the coming weeks). If you would like to find out more about the transition to a CIO we will be hosting a live Q&A session with SarcoidosisUK Executive Chairperson Peter Tichbon on Wednesday 10th November at 6pm, which you can join via this link: https://zoom.us/j/92526749016.

Our commitment remains to provide the highest level of support and information to the sarcoidosis community,

whilst raising awareness on a national level and investing in world-leading research. Thank you for your continued support!



Register for the Virtual Cardiac Sarcoidosis Patient Day

On 17th November, SarcoidosisUK and The Royal Brompton & Harefield Hospitals will be hosting a virtual Cardiac Sarcoidosis Patient Day.

This will be our fourth patient day of the year and the first ever patient day held by SarcoidosisUK and The Royal Brompton & Harefield Hospitals dedicated to Cardiac Sarcoidosis. All previous patient days have been very well received and this event promises to follow in their footsteps!

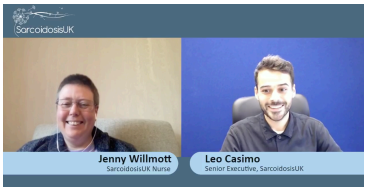
This patient event is free to attend, however if you would like to make a donation to SarcoidosisUK it would be extremely appreciated. Click the button below to register for our Cardiac Sarcoidosis Patient Day!

Register for the Cardiac Sarcoidosis Patient Day

London Virtual Marathon & Other Events

We would like to thank all of our incredible fundraisers who took part in events across the UK this month! October kicked off with some fundraisers completing the Virtual London Marathon, whilst others participated in events as the Manchester Marathon, Loch Ness Marathon, Royal Parks Half Marathon and many more. SarcoidosisUK is grateful to each and every person who supported the charity this month, whether you took part in an event or supported those who did by donating, every pound raised helps to make a huge difference. Thank you!

Fundraise for SarcoidosisUK



Sarcoidosis and Mental Health Q&A Video

In honour of World Mental Health Day on the 10th of October, we hosted a live Q&A on the topic of sarcoidosis and mental health. Leo was joined by SarcoidosisUK Nurse Jenny who spoke to us about why people with chronic conditions such as sarcoidosis may struggle with their mental health as well as highlighting what support options are available.

If you would like to watch the video back or find out more about mental health support, visit our Sarcoidosis and Mental Health webpage by clicking the button below.

Visit our Sarcoidosis and Mental Health Webpage

Introducing our new SarcoidosisUK Helpline Nurse Rachel

We are thrilled to welcome Rachel the team as our new helpline nurse. We now have a team of three fantastic nurses offering free and confidential support to anyone affected by sarcoidosis.

Rachel has worked for many years within the NHS, supporting people with long-term health conditions. She is trained in health education, cardiac nursing and diabetes care. She currently works as a Diabetes specialist nurse in general practice. Rachel was diagnosed with chronic sarcoidosis in 2016 so has faced many of the challenges shared by the sarcoidosis community and is therefore very happy to be joining the existing SarcoidosisUK Nurse Helpline team in offering support and advice to those dealing with the condition on a daily basis. Rachel enjoys escaping to the country with her husband and dog in their much loved camper van called Marge!

To find out more about the SarcoidosisUK Nurse Helpline, click the button below.

Find out More about the SarcoidosisUK Nurse Helpline

2022 SarcoidosisUK Calendars Now Available!

Get prepared for the New Year with our calendar that is now available to purchase on the SarcoidosisUK Store! The 2022 calendar has been designed using photographs from the "Global Project for a Global Disease" that was completed by Joanne Cudmore, Daniela Cruz and Peter Devonald. The calendars also include inspirational quotes from the sarcoidosis community - click the button below to take a look!

The 2022 SarcoidosisUK Calendar

New SarcoidosisUK Support Group in Lancashire!

We are pleased to announce that we are setting up a SarcoidosisUK Support Group in Lancashire. The aim of this group is to provide a place for those affected by Sarcoidosis to meet others, to share their experiences, to be a friendly face, and to learn from each other.

If you would like to be added to the mailing list for the Lancashire Support Group and be informed when the first meeting will take place, please send an email to info@sarcoidosisuk.org

Luke Hopkins' Season Review

In 2019, a chance meeting between a young, up and coming motorcycle racer, Luke Hopkins, and motorcycle enthusiast and sarcoidosis patient Mike Woodward provided the catalyst for a partnership between Hopkins Racing and SarcoidosisUK that has continued for three seasons.

This year Luke stepped up to the British Superbike Championship (BSB), the highest level of motorcycle racing in the UK. It is considered by many to be the most competitive and high profile domestic championship in the world and race meetings regularly attract crowds in excess of 30,000 with all of the races being shown live on Eurosport or Quest.

Luke is planning a second season in BSB in 2022 and he will once again carry the SarcoidosisUK logo on his bike and leathers. Watch out for him on TV and if you attend any meetings be sure to visit Team Hopkins in their garage during the pit lane walkabout when they'll be handing out signed posters of Luke that bear the SarcoidosisUK logo!

Read Luke's 2021 Season Review

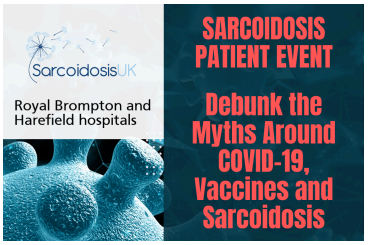
ERN-LUNG Population Registry

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 by clicking the button below.

Join the Registry



Debunk the Myths Around COVID-19, Vaccines and Sarcoidosis

On 28th October, SarcoidosisUK and The Royal Brompton & Harefield Hospitals hosted a virtual patient event called "Debunk the Myths Around COVID-19, Vaccines and Sarcoidosis". Thank you to the patients and speakers who joined us for this fantastic event. We will be sharing a recording of the event on our website soon for those who could not make it.

We have created a post-event survey to collect feedback about the event in order to make sure our future Patient Days as effective as possible. This survey also includes questions about your experience of the COVID-19 pandemic. Your responses will be used to help us understand how the pandemic has affected sarcoidosis patients and inform our future work in this area.

Complete the Post-Event Survey

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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SarcoidosisUK is a registered charity
Charity Number 1063986