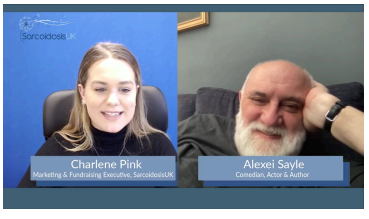
Sarcoidosis and Coronavirus Survey | Alexei Sayle Interview | Vaccines Q&A | Donate

February Newsletter

Sarcoidosis and Coronavirus Survey Part 2

SarcoidosisUK has created a second Sarcoidosis and Coronavirus Survey to collect information on how the pandemic is currently affecting sarcoidosis patients. This includes their experience of shielding, COVID-19 vaccinations and the most recent national lockdown. We will use this information to represent sarcoidosis patients and contribute to a greater understanding of how they are affected by coronavirus. Please complete our survey today so that we can continue to make sure that the voices of sarcoidosis patients are heard.

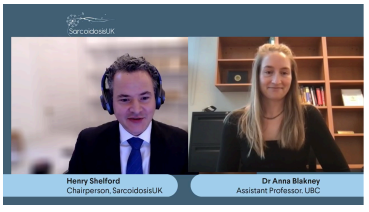
Take the Survey



Interview with Alexei Sayle

On the 17th February, SarcoidosisUK Marketing and Fundraising Executive Charlene interviewed comedian Alexei Sayle about his sarcoidosis journey. Alexei very kindly gave up his time to talk about his diagnosis, career and experience of lockdown. Thank you for helping us to raise awareness of sarcoidosis Alexei!

Watch the Interview



Vaccines Q&A with Dr Blakney

On the 3rd February, SarcoidosisUK Chairperson Henry Shelford hosted a live Q&A about the COVID-19 vaccines with Dr Anna Blakney, Assistant Professor at University of British Columbia and a specialist in RNA vaccines.

This is our tenth coronavirus Q&A video and it answers important questions put to us by sarcoidosis patients about the science behind the COVID-19 vaccines. You can find all of our coronavirus information for sarcoidosis patients on our website, including FAQs and

previous Q&A videos.

Our next vaccines Q&A video will take place on the 9th of March at 2pm. If you have any questions you would like to submit for the Q&A, you can do so using the form at the bottom of our Vaccines FAQ Page.

Watch the Vaccines Q&A

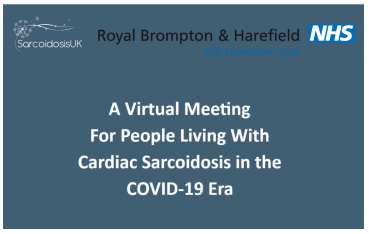
In memory of Robin Hunte

It is with a heavy heart that we remember Robin Hunte, who passed away on 14th January 2021.

Robin was an extremely valued member of our SarcoidosisUK London Support Group, and we know that many people will be deeply saddened by this news.

“He will be missed by his Mum, siblings, wife, children and grandchildren. He was very engaged in various community groups and it doesn’t surprise us that he invested the same energy into SarcoidosisUK. He spoke often of the group and we know it was a great support to him.”

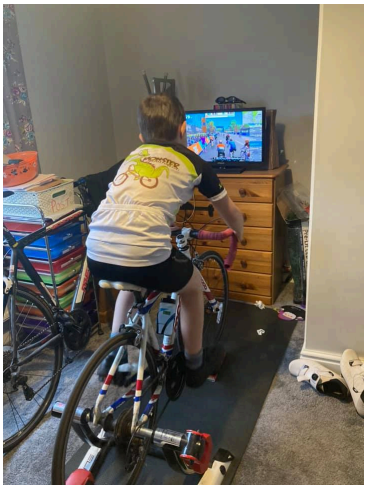
Our thoughts are with Robin’s family during this difficult time. We will continue to face sarcoidosis together, so that no one is alone.



A Virtual Meeting for Cardiac Sarcoidosis Patients in the COVID-19 Era

On 10 February, SarcoidosisUK attended The Royal Brompton Cardiac Sarcoidosis Team's Virtual Meeting for Cardiac Sarcoidosis Patients in the COVID-19 Era. We also livestreamed the event to our social media pages so if you missed it, you can catch up now!

Watch the Virtual Meeting



Ewan's 100 Mile Cycle Challenge

A big thank you to 10-year-old Ewan, who is completing a 100 mile cycle challenge this month to raise money for SarcoidosisUK!

Any donations to help him on his way would be extremely appreciated – please consider donating to his fundraiser.

Keep up the good work Ewan - you're a superstar!

If you have are interested in fundraising for SarcoidosisUK, please get in touch with Charlene, our Marketing and Fundraising Executive at charlene@sarcoidosisuk.org

Support Ewan's Challenge

Research Priorities For Progressive Pulmonary Fibrosis Survey

Pulmonary fibrosis can affect sarcoidosis patients. Like sarcoidosis, pulmonary fibrosis is an under-researched area that requires greater attention.

SarcoidosisUK supports Action For Pulmonary Fibrosis and their Survey on Research Priorities For Progressive Pulmonary Fibrosis. The aim of this important survey is to identify unanswered questions around progressive pulmonary fibrosis.

This is an exciting opportunity for anyone connected to pulmonary fibrosis to help set the priorities for future research. If you have been diagnosed with pulmonary fibrosis, or you are a carer, relative, bereaved family member or healthcare profession, please complete this short survey. Let's make sure that the voices of sarcoidosis patients who are affected by pulmonary fibrosis are heard.

Have Your Say

Rare Disease Day 2021

SarcoidosisUK is proud to support Rare Disease Day taking place this Sunday 28th February.

Awareness must continue to be raised amongst the general public and decision-makers about rare diseases and their impact on patients' lives, including sarcoidosis.

We will not stop our vital work until a cure for sarcoidosis has been found. Until then, we will continue to work hard to raise awareness of sarcoidosis and provide quality information and support to those living with the disease.

Rare is many. Rare is strong. Rare is proud.

Get Involved!

Bromley F.C. Scooters

Thank you to Riley Scooters, who have teamed up with our partner Bromley F.C. to support SarcoidosisUK! Not only are they giving Bromley supporters £25 off any order of a scooter, Riley Scooters will donate £20 from every order from a Bromley supporter to Sarcoidosis UK! Use the code "bromley25" to get your discount.

Please ensure that you have read the regulations about where you can legally use electric scooters in the UK before purchasing.

Check Out The Bromley F.C. Scooters

Misdiagnosis of Sarcoidosis

SarcoidosisUK Patient Ambassador Jacqui Newton and former London Support Group Organiser Mike Howie were recently interviewed by medical journal The

Lancet, for an article about the misdiagnosis of sarcoidosis.

The article highlights problems in diagnosis of sarcoidosis for doctors and patients alike and the importance of the definitive biopsy.

A huge thank you to Mike and Jacqui for all that you do for sarcoidosis patients and SarcoidosisUK.

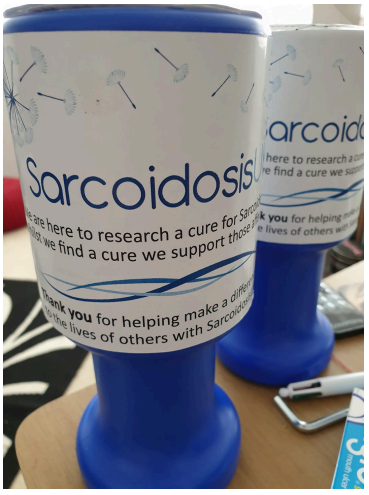
Read the Article

Sarcoidosis Patient Day
1st April 2021
(10:00 – 16:00 GMT)

Save the Date! Sarcoidosis Patient Day

We are thrilled to announce that the first ever Royal Brompton Hospital and SarcoidosisUK Sarcoidosis Patient Day will take place on 1st April 2021 (10:00 – 16:00 GMT). This will be a free virtual event created specifically for sarcoidosis patients, where you'll be able to hear patient-centered talks from a line-up of specialists that are renowned in their field.

We'll be in touch soon with more information about how to register.



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