May Newsletter

Exciting Research Update!

In January 2020, SarcoidosisUK agreed to grant £59,847 to 50% co-fund a project with Asthma and Lung UK at the University of Southampton being led by Prof. Mark Jones. The researchers aimed to improve the understanding of lung scarring in sarcoidosis patients and possible treatment options by studying lab-grown sarcoid tissue.

"Our understanding of why scar forms and progresses in some patients with sarcoidosis is still very limited. This project has identified that the 3D scar model we have developed can help to address this challenge including the study of the effects of different possible treatment. There are still many steps to directly translate findings to patients, but ultimately we hope this will support the development of better targeted treatments for patients." - Professor Mark Jones

Our hope is that these findings will greatly improve our understanding of lung scarring in patients with sarcoidosis, in particular those undertaking long term steroid treatment. We hope that this research project will inspire further research which looks at scar forming cells and sarcoidosis treatments to help improve outcomes for patients.

Read the Latest Research Update Here

Submit your questions for Sarcoidosis Patient Day!

We will hear from a variety of speakers on a range of topics. This year there is a big focus on patient involvement with lots of time dedicated to questions. This is a brilliant opportunity to have your questions answered by sarcoidosis consultants!

You can submit as many questions as you would like and we will try to answer as many as possible on the day.

Please submit your questions by the 6th of June.

Submit your Patient Day Questions

Diagnostics Journal Special Edition

The Diagnostics Journal is doing a Special Issue entitled 'Sarcoidosis: From Diagnosis to Management' which will be of interest to medical professionals. We were delighted to be asked to write a letter of support asking for medical and research submissions for the edition! We hope that this Special Issue can inspire further research and development to help improve outcomes for patients and are excited that they're planning this edition. We are always grateful for the opportunity to provide our support and help to raise awareness of sarcoidosis.

If you'd like to read more about the edition, please click the button below.

Find Out More

10 priorities the government needs to take seriously

Lung conditions receive just 2.5% of public funding. No one should be left struggling to breathe.

The Lung Research and Innovation Group have set the 10 priorities the government needs to take seriously to fix the lung research pipeline and fix the nation’s lung health. We need the government and key stakeholders, including funders of research and innovation, to act to help improve diagnosis, treatment, and save lives.

The Lung Research and Innovation Group is a national group of patient advocacy charities, expert organisations and leading researchers determined to drive progress in respiratory research and innovation.

Download the Full Report Today

Welcome to our new trustees!

We would like to welcome four new trustees to that SarcoidosisUK team, Roma Armstrong, Dawn Clements, Dawn Farrar and Emily Sturdy.

- Roma Armstrong has a background in research. She has also worked for the Scottish Government, as well as leading, managing and delivering clinical research within the NHS.
- Dawn Clements is currently Director of Fundraising and Engagement for the Forget Me Not Children's Hospice in Yorkshire.
- Dawn Farrar joins SarcoidosisUK having recently retired from her role as Director of Research and Advocacy with a medical health charity.
- Emily Sturdy is currently Head of Supporter Experience at Parkinson's UK, and had a career in consumer publishing for over 12 years before moving to the healthcare charity sector in 2013.

We're delighted to have them onboard! Keep an eye on our socials for their individual introductions.

Thank you to our amazing fundraisers!

SarcoidosisUK would like to say a huge thank you to the following May fundraisers;

- Criminal Justice Inspection Northern Ireland Team took on the Belfast Marathon Team Relay in memory of Meloney's late husband, Alan McVeigh;
- Katie ran the Hackney Half to raise awareness and vital funds;
- Jess, her brother, and friends ran the Great Manchester Half Marathon in support of her Dad;
- Callum ran the Edinburgh Half Marathon in memory of a loved one;
- Milton Keynes Scale Model Club chose SarcoidosisUK as one of the charity recipients of their annual ModelKraft show;
- Chloe braved dizzying heights on a skydive in memory of her mum, Trish!

As a small charity, fundraisers make such a big difference to the work we're able to do. Thank you!

If their fundraising has inspired you to embark on your fundraising journey, please don't hesitate to reach out to Eva at eva@sarcoidosisuk.org for fundraising support or check out our fundraising

page below for inspiration - we can't wait to hear from you!

Start Your Fundraising Journey Today!

We Launched Brand New Greetings Cards!

These cards were designed by Jane Vellender, an amazing artist, and are perfect for any occasion. These cards help to spread sarcoidosis awareness among those closest to you while also supporting the charity. Check them out on our shop website today!

Order Greetings Cards Here

Check out the Go Blue Gallery

For Sarcoidosis Awareness Month this year we asked buildings and landmarks across the country to light up in blue to shine a light on sarcoidosis. Throughout the month, we had over 40 locations across the UK lighting up!

We had some amazing volunteers head down to some of these locations to take photos. We were so impressed by how many of you got involved and sent over your incredible images, thank you for making this Sarcoidosis Awareness Month so amazing!

We've compiled some of your amazing images together to show the support we received from across the UK. Click the button below to see the gallery.

Find the Gallery Here

Share Your Sarcoidosis Journey

Have you been reading our Sarcoidosis Stories?

Your voice is important!

Everyone has a different experience with sarcoidosis and so it is important to highlight and share as many people's journey with sarcoidosis as possible.

If you are affected by sarcoidosis, whether as a patient, a loved one, a carer, or maybe even a researcher, we want to hear your sarcoidosis story.

If you'd like to share your sarcoidosis story, please get in touch with our Charity Ambassador Kemi on kemi@sarcoidosisuk.org.

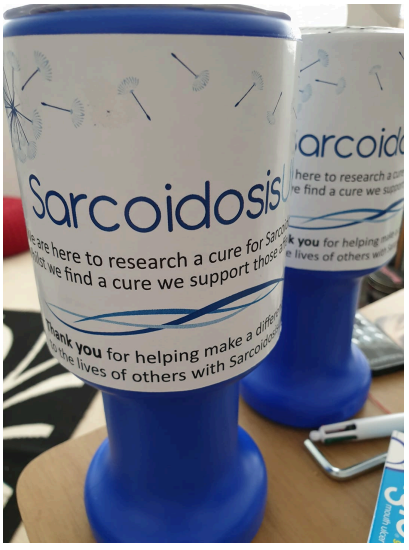
SarcoidosisUK Upcoming Support Group Meetings

Upcoming Support Group Meetings

Please see below for the dates of our upcoming support group meetings. If you would like to attend, please get in touch with Leo on leo@sarcoidosisuk.org who will put you in touch with your local group. Anyone affected by sarcoidosis is welcome - so come along and join us!

- Scotland (Edinburgh) Group Meeting - 8th June 2pm (In-person)
- North West Group Meeting - 11th June 6:30pm (Virtual)
- Bristol Group Meeting - 25th June 7:30pm (Virtual)
- East Anglia Group Meeting - 13th July 1pm (In-person)
- Scotland (Glasgow) Group Meeting - 16th July 6pm (In-person)
- Bristol Group Meeting - 16th July 7:30pm (Virtual)

Find out more about our Support Groups



Support SarcoidosisUK

Please consider donating 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.

Every donation will help make a difference to SarcoidosisUK and ensure that we can continue to support people affected by sarcoidosis. Make your donation by clicking the button below!

Donate

SarcoidosisUK
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SarcoidosisUK is a registered charity
Charity Number 1063986