



November Newsletter



SarcoidosisUK's Condition Insight Report

Sarcoidosis is a complex and often misunderstood rare disease that can cause many debilitating symptoms. This poses a challenge for individuals with sarcoidosis who are seeking disability benefits, as assessors may not fully understand the condition.

SarcoidosisUK has worked with Independent Assessment Services to create a Condition Insight Report for their Personal Independence Payment (PIP) assessors to help address this problem. Assessors will now be advised to refer to this report when preparing for their assessments as it provides accurate and up-to-date information about sarcoidosis, emphasising its systemic nature and addressing misconceptions. We hope this report will help ensure that individuals living with sarcoidosis receive the support they deserve.

Sarcoidosis affects everyone differently; therefore the Condition Insight Report may not cover all possible symptoms and information. Our report emphasises the variation in symptoms and severity that people with sarcoidosis experience to account for this.

This is the second assessment provider we have worked with to create a Condition Insight Report and we hope to work with more in the new year to improve the awareness of sarcoidosis among PIP assessors.

[Read the Condition Insight Report Here](#)



Infiximab News

Infiximab has now been approved by NHS England for adults with refractory sarcoidosis.

Infiximab treatment was approved in July 2020 for patients with neurosarcoidosis and we are pleased that it has now been approved for wider use.

Please click the link below to read the committee decision, information about Infiximab treatment, criteria, a patient pathway, and more!



BTS Interstitial Lung Disease Registry

The 10-Year Report for the BTS Interstitial Lung Disease (ILD) Registry is now out!

The BTS ILD Registry holds national longitudinal data for two disease areas, idiopathic pulmonary fibrosis (IPF) and sarcoidosis. As of February 2023 this was expanded to all fibrosing ILDs.

This report is a celebration of the last decade of work undertaken to create, maintain and expand the Registry to improve quality of care for patients. We would like to say a huge thank you to everyone involved, including our Senior Executive, Leo Casimo.

[Read the Report Here](#)

BTS Winter Meeting

Our Executive Chairperson, Sue Wilson, attended the British Thoracic Society Winter Meeting. This three day event brings together health care professionals, researchers, charities, pharmaceutical and biotech representatives to explore the latest developments in lung health.

There was a busy programme of lectures and symposia, poster presentations and discussions. SarcoidosisUK partnered with Action for Pulmonary Fibrosis to share our Sarcoidosis and the Lung leaflets.



Thank You to Our Fundraisers!

SarcoidosisUK would like to say a HUGE thank you to our exceptional fundraisers this month! Their unwavering dedication to both raising funds and spreading awareness for SarcoidosisUK is truly amazing.

- Kimberly managed to complete 200 cartwheels every day this month, raising both awareness and funds for SarcoidosisUK! She took on this challenge in support of her grandmother and in memory of her Auntie Lisa Rosenthal.
- Nicholas competed in a Charity Boxing Match and won! He chose SarcoidosisUK in support of his Mum who has sarcoidosis.

Your efforts are making such a big impact, and we're incredibly proud.

If their efforts have 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!

[Fundraise for SarcoidosisUK](#)



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.



Our 2023 Christmas Card is Now Available!

We are thrilled to announce the winner of our Christmas Card Competition, Sandra Compton-James. Congratulations!

You can now order this fantastic design, spreading the holiday cheer to all your loved ones near and far.

A pack of 10 cards made from recycled materials for £5.50, plus free postage when you buy 3 packs or more!

All purchases made in the SarcoidosisUK Shop are considered donations and enable us to continue our vital work. Visit our website today and make this holiday season extra special with our Christmas cards.

You can also grab winning designs from previous years from the [SarcoidosisUK Store](#), so order now to avoid missing out.

[Buy Our 2023 Christmas Card Here](#)



12 Days of Christmas

Join us as we kick off our annual 12 Days of Christmas Advent Calendar.

Starting tomorrow, watch our social media platforms for daily posts and engage with our Advent Calendar each weekday to help us raise awareness for sarcoidosis among your family and friends this holiday season. Let's spread the cheer and support together. Are you ready?

Upcoming Support Group Meetings

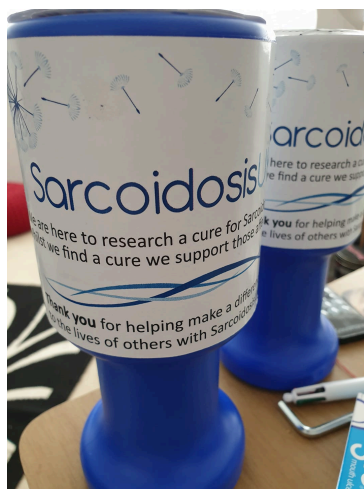
Please see below for the dates of our upcoming support group meetings. If you would like to attend, please get in touch with Leo on leo@sarcoidosisuk.org who will put you in touch with your local group. Anyone affected by sarcoidosis is welcome - so come along and join us!

- East Anglia Group Meeting – 2nd December 2pm (Virtual)



- London Group Meeting – 5th December 7pm (Virtual)
- Scotland (Edinburgh) Group Meeting – 9th December 2pm (In-person)
- North West Group Meeting – 12th December 6:30pm (Virtual)
- Scotland (Glasgow) Group Meeting - 19th December 6pm (In-person)
- Bristol Group Meeting – 19th December 7:30pm (In-person)

[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
214 China Works
100 Black Prince Road
London SE1 7SJ
info@sarcoidosisuk.org
www.sarcoidosisuk.org



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