February Newsletter

Today is Rare Disease Day!

Living with a rare disease can be isolating but whilst these conditions are uncommon individually, together there are 300 Million people living with over 6,000 rare diseases worldwide. Today, we want to elevate the voices of the sarcoidosis community by sharing their journey with sarcoidosis to give them the visibility they deserve. We will be sharing our sarcoidosis stories throughout the day on our Twitter (X) account! Click below to see all of our sarcoidosis stories.

Read our Sarcoidosis Stories

Thank you to our amazing fundraisers!

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

- Christion who took on the Newcastle Winter Warmer Run and raised £1,300
- Caitlin who took part in the Battersea Park 5K in support of her Dad and raised £1790
- The Marlow Cheetah's from Richter who completed 6,100 press-up's in a week and raised £605

As a small charity, fundraisers make such a big difference to the work we're able to do. If you've been inspired to take on a challenge of your own, please email our Marketing and Fundraising executive Eva on eva@sarcoidosisuk.org.

Start Your Fundraising Journey Today

The SarcoidosisUK Nurse Helpline

The Nurse Helpline is a free and confidential telephone helpline. We help support patients and anyone else affected by sarcoidosis. All calls are taken by the SarcoidosisUK Nurses who have personal and/or professional experience of sarcoidosis.

The Helpline Reaches 3500 Calls!

This month, our Nurse Helpline officially reached 3500 calls made! Our nurses have work tirelessly to support so many people affected sarcoidosis, and we are so proud of all of their achievement. We thought this month would be the perfect time to highlight all of their amazing work - **Thank you to the SarcoidosisUK Nurses!**

Meet Jo, the first SarcoidosisUK Nurse

"When the helpline was proposed I felt strongly that this was something I should be involved with as I had a breadth of knowledge, and a strong conviction that people needed to be able to talk. Either with someone who understood their experience or, who was able to help them negotiate the NHS."

Read the Rest of Jo's Story

Nurse Rachel's Sarcoidosis Story

"This summer I have notched up 3 years of service on the Nurse Helpline. I was so pleased to join the team after the help I was offered following my sarcoidosis diagnosis in 2016. I love working for SarcoidosisUK as it is a very proactive charity. There is something to support everyone whatever your personality type - from local support and Facebook groups to opportunities for participation in vital research. And of course the Nurse Helpline! It helped me feel less lonely on my sarcoidosis journey and enabled me get a better perspective on my condition. You are always so welcome to book a call with us!"

In December, Rachel shared her Sarcoidosis Story with us. Click the button below to read her

full story.

Read Rachel's Story

Thank you to the Hospital Saturday Fund!

Last year, the Hospital Saturday Fund granted us **£2,000** to help us fund our Nurse Helpline. SarcoidosisUK would like to say a BIG thank you for their support and recognition of the amazing work that our nurses do supporting those affected by sarcoidosis. We are extremely grateful and it has made a huge difference - **thank you!**

In other news...

APF Focus Group Opportunity

Do you or someone you love have pulmonary fibrosis? Action for Pulmonary Fibrosis (APF) want to hear from you.

Action for Pulmonary Fibrosis (APF) are running a small discussion group to hear your views about research and involvement so that they can build a network which ensures that research meets the needs of everyone affected by pulmonary fibrosis. Whether you are a patient, carer, or loved one, APF want to hear your thoughts.

The provisional date is Monday 11th March 2024 from 10am to 12:30pm. The discussion will be online and will be informal.

If you can attend or are interested in APF's work, please contact involvement@actionpf.org.

A New Study for Diagnosing Sarcoidosis

NIH have funded the development of a tool, a simple blood test, that has the potential to quickly diagnose sarcoidosis. Their initial tests were able to differentiate patients who had sarcoidosis from those with other respiratory diseases.

"Using a blood test will help diagnose faster, particularly in those organs that are more challenging to biopsy and with less harm to the patient." - James Kiley, Ph.D., Director of the Division of Lung Diseases at the National Heart, Lung, and Blood Institute, part of NIH.

Many people with sarcoidosis wait a long time to be diagnosed. Although further, larger studies are needed, we are very excited about the prospect of this test and the possibility it presents for

helping to speed up the diagnosis process for sarcoidosis. Click below to read more.

Find out More Here

Clinical Trials

For many years there has been little interest and research into sarcoidosis by pharmaceutical companies. That is now changing! New clinical trials specifically designed for sarcoidosis are taking place in the UK as well as USA and other countries. Some of the UK clinical trials have had new investigation sites added.

Find out more about sarcoidosis clinical trials actively recruiting in the UK by clicking the button below.

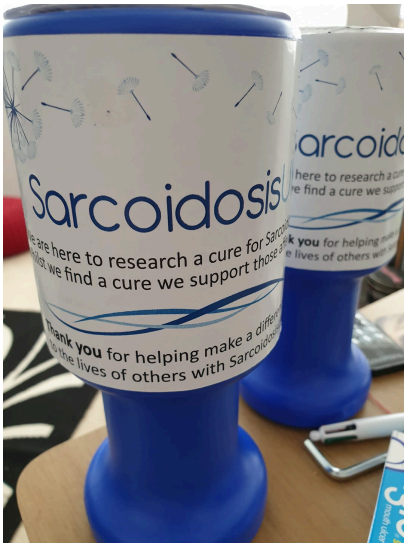
Find out More About Clinical Trials

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 – 2nd March 2pm (In-person)
- East Anglia Group Meeting – 16th March 2pm (In-person)
- London Group Meeting - 18th March 7pm (Virtual)
- Bristol Group Meeting – 19th March 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

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SarcoidosisUK is a registered charity
Charity Number 1063986