



[Sarcoidosis Patient Day](#)

[Interview with Karen Duffy](#)

[Interview with Shelley Garland](#)

[Donate](#)

April March Newsletter



Royal Brompton and Harefield hospitals

Sarcoidosis Patient Day

1st April 2021
(10:00 – 16:00 BST)

Sarcoidosis Patient Day

On the 1st of April 2021, we hosted the first ever [Royal Brompton and Harefield Hospitals and SarcoidosisUK Sarcoidosis Patient Day](#). This was a free virtual event created specifically for sarcoidosis patients, where we heard patient-centred talks from leading specialists.

If you missed any of the talks, or would like to watch them again, [click here](#) to see the recordings and transcripts for each session.

We would love to hear your feedback about the Sarcoidosis Patient day in order to make sure our future events are as effective as possible. Let us know what you thought by filling in our short [post-event survey](#).

Click [here](#) to find out more about becoming a Royal Brompton and Harefield hospitals member.

[Watch the Patient Day Recordings](#)



Interview with Karen Duffy

On the 14th April, we hosted a [live interview](#) with Karen “Duff” Duffy, an American writer, model, television personality, and actress. In 1995, Duff was diagnosed with neurosarcoidosis. Since then, she’s written two books about her experience living with sarcoidosis and chronic pain.

As part of Sarcoidosis Awareness Month, we chatted to Duff about her journey with sarcoidosis, how the disease has affected her life and why she thinks raising awareness is so important.

[Watch the Interview](#)

Juliet's Inspiring Walking Challenge



Juliet has always wanted to run a marathon. Unfortunately she was diagnosed with sarcoidosis in 2004 - the disease attacked her lungs and also caused a problem with her heart, which put an end to her marathon dream.

This Sarcoidosis Awareness Month, Juliet decided her dreams can still come true.

"I'm taking part in my own version of a marathon to help raise awareness of my disease and raise funds to help find a cure to save lives for those that come after me. I am aiming, under Doctor's advice, to walk an additional 3000 metres in 30 days in honour of Sarcoidosis Awareness Month in April.

To most of you an additional 3km, or just under 2 miles, in a month probably doesn't seem very far, even verging on the ridiculous, until I tell you that most days I struggle to walk more than 100 metres a day. This challenge will aim to make me double the distance I walk daily.

Add to this that I'm also permanently attached to a machine pumping oxygen into me. This is because I have less than one lung's capacity left available and my lungs are only 20% efficient at taking in oxygen from the air I breathe. It will be quite a challenge!"

[Support Juliet's JustGiving Page](#)



Shelley Garland Interview

On the 28th April, SarcoidosisUK Marketing and Fundraising Executive Charlene hosted a [live interview](#) with Shelley Garland, whose daughter sadly passed away on the 2nd March 2021 at the age of 32 from neurosarcoidosis. Thank you to Shelley who joined us to share Suzi's story and raise awareness of the neurosarcoidosis.

You can read more about Suzi's story [here](#).

[Watch the Interview](#)



SarcoidosisUK Virtual Bake Off

In honour of Sarcoidosis Awareness Month we're hosting a [bake off](#), where the winner will receive a £20 voucher to spend in our SarcoidosisUK Store!

Since we won't be able to taste your home-baked goods, we're asking you to submit a picture instead (so stand-out presentation is the recipe for success!). What you decide to bake is completely up to you - cookies, cakes, muffins, cupcakes, we want to see them all!

[Find Out More and Take Part!](#)

The SarcoidosisUK Nurse Helpline hits an important milestone!

In April, the [SarcoidosisUK Nurse Helpline](#) hit an incredible milestone - 2,000 scheduled calls made by



our SarcoidosisUK Nurses since the service began!

The SarcoidosisUK Nurse Helpline exists to provide anyone affected by sarcoidosis that much needed extra information and support - and in the past year, this has been more vital than ever.

Congratulations to Jo and Jenny, the amazing SarcoidosisUK nurses. They have worked tirelessly to help so many people through this service, and we cannot thank them enough for all they do for SarcoidosisUK.

[Find Out More About our Nurse Helpline](#)



Eileen's Cold Swims

Eileen, one of our incredible SarcoidosisUK volunteers, has been doing daily cold swims since November 2020 to raise funds for SarcoidosisUK.

"I was diagnosed with the sarcoidosis almost five years ago during a two week hospital admission. I lost my sight, and was seriously ill. I was forced to give up work, my driving licence was revoked and I had to learn to live alongside this disease. My Sarcoidosis affects my brain, eyes, heart, skin, mouth and joints. There is no cure. Swimming is a vital way I manage my symptoms and reduce the pain and fatigue I endure every single day."

From smashing through ice and enduring freezing temperatures to completing sea, quarry and waterfall swims, Eileen has not only pushed herself physically and mentally, but also managed to raise over £2000 for SarcoidosisUK!

Unfortunately Eileen was recently involved in a car accident, so had to take a break from her cold swims challenge for a little while. As she recovers, we'd love to show her some support from the SarcoidosisUK community and help her reach her fundraising target! If you can, please consider making a donation to Eileen's [JustGiving page](#).

[Support Eileen's Challenge](#)



Sarcoidosis Awareness Month Artwork

In honour of Sarcoidosis Awareness Month, we asked you to submit your photos to our virtual Warrior Photo Wall to serve as a reminder that you are not alone and to celebrate the sarcoidosis community.

All of your submissions have now been used to create this mosaic, which is available to download as a PDF or purchase as a canvas print in the [SarcoidosisUK Store](#).

Thank you to everyone who submitted your photos, we loved seeing all of your entries.

[Visit the SarcoidosisUK Store](#)

Mark's Cycling Challenge

SarcoidosisUK Superstar Thank you Mark!



Over the course of 2021, Mark will be challenging himself with the following cycling events to raise funds for SarcoidosisUK:

- Tour of the Pennines - 41 Miles of Hills - 8th May
- Tour of the Peaks - 61 Miles of Hills - 23rd May
- Cheshire Cat - 108 miles including "Mow Cop" - 12th September

His last and final challenge will be the Manchester Marathon on 10th October!

Having been diagnosed with sarcoidosis in 2019, Mark is now wanting to help others by raising funds for SarcoidosisUK that will go towards finding a vital cure and supporting those living with the disease.

We are so grateful to Mark for all that he is doing and would love to see him receive as many donations as possible.

[Visit Mark's JustGiving Page](#)



5k May

Sign up for our next event [#5kMay](#)

We've teamed up with Run For Heroes and asking you to participate in a 5k of any kind this May!

What is 5K May?

One month of coming together for better! You can do your 5K anywhere, anytime with anyone. You can run, roll, walk, cycle or even swim if you want to... It's about getting out and feeling good while doing it. Complete your 5k, donate £5 to SarcoidosisUK and nominate 5 of your friends to take part. After donating you'll unlock an exciting goodie bag too!

How to get involved!

- Participate: Run, walk, roll your 5K, do whatever suits you
- Donate: Donate £5 to a cause close to your heart
- Nominate: Nominate your friends to take part
- Rewards: Runners & movers get rewards

[Get Involved](#)

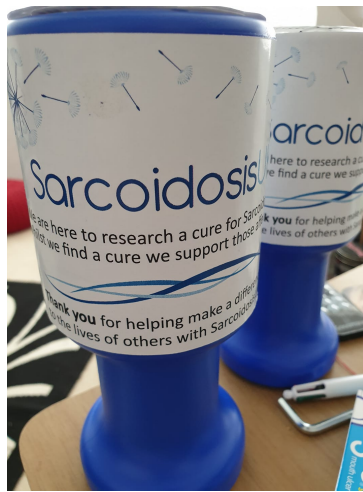


SarcoidosisUK Hertfordshire Support Group

SarcoidosisUK run a network of Support Groups across the UK. Our groups are an opportunity for you to meet with people who understand what you're going through, to share experiences of sarcoidosis and learn from each other.

If you live in Hertfordshire and would like to meet others with sarcoidosis, send an email to info@sarcoidosisuk.org to register your interest in joining the SarcoidosisUK Hertfordshire Support Group and find out more. Everyone is welcome so come along and join us!

Please note, all of our support groups are currently meeting online due to the COVID-19 Pandemic.



Support SarcooidosisUK

Please consider [donating](#) or [becoming a member](#) to support our work funding research into a cure and providing services to sarcooidosis patients. We need your support to continue the work we do.

[Donate](#)

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



SarcooidosisUK is a registered charity
Charity Number 1063986

This email was sent to {{ contact.EMAIL }}.
You received this email because you are registered with SarcooidosisUK.
[We hope you like our newsletters. If you don't, simply unsubscribe here.](#)

© 2020 SarcooidosisUK