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SARCOIDOSISUK MONTHLY NEWS

MARCH 2018

Dear Friend of SarcoidosisUK,

We have been very busy in the office, making sure we continue to provide the best information and support for anyone affected by sarcoidosis. I am very pleased to announce a new FAQ page on our website, an updated Information Leaflet as well as another milestone for the Nurse Helpline! Read on to find out more...

Please help us to welcome the newest member of the SarcoidosisUK team, **Marcin Wazsak**, who will be in charge of all our fundraising and marketing. Welcome Marcin!

Finally, welcome to spring! 🌸 I hope that the warmer weather has eased the pressure on those who have winter flare ups.

Best wishes,
Jack Richardson, SarcoidosisUK Executive Officer

NEW SARCOIDOSIS FAQ PAGE

Last year, you gave us your ideas and suggestions via the SarcoidosisUK Supporter Survey. Many of you asked for an FAQ page on the website. We thought this was a fantastic idea!

We went away and have spent the last few months writing and reviewing our FAQ

page. The FAQs have been written with the help of a number of patients and experts including the SarcoidosisUK Nurse Helpline staff, **Dr M. Wickremasinghe** (Imperial College London), **Dr H. Adamali** (Southmead Hospital) and our SarcoidosisUK Norwich Support Group. Thank you to everyone involved!

The FAQ page is now live! There is lots of information on many sarcoidosis-related topics to help anyone affected by sarcoidosis understand more about what they are going through.

We think these FAQs are a great resource. However we know they can be added to - please use the form on the page to submit any questions you think are missing. Over time we will do our best to collate these, consult our experts, and add them to the list.


SARCOIDOSIS FAQ

SARCOIDOSIS AND THE HEART LEAFLET

We have carefully reviewed and updated another of our Patient Information leaflets with the help of a team of experts.

Consultant Cardiologists **Dr M. Thillai** (Papworth Hospital), **Dr A. Varnava** and **Dr M. Wickremasinghe** (Imperial College) have all contributed to the new version.

You can read and download the leaflet for free on our website. If you would like to order this or any of our other leaflets, **please get in touch**.

Treatment		Who We Are
Cardiac Sarcoidosis	Pulmonary Hypertension	<p>SARCOIDOSIS AND THE HEART</p>  <p>SarcoidosisUK</p>
Diagnosis	Medications are used to relieve symptoms and improve the prognosis of the blood vessels.	
Diagnosis	Your doctor may prescribe medication to suppress the sarcoidosis.	
Diagnosis	• corticosteroids in tablet form, usually prednisolone. These medications must be used for a number of years, or even permanently.	
Diagnosis	• other medicines that suppress the immune system, for example methotrexate, mycophenolate or azathioprine.	
Diagnosis	These drugs suppress the inflammation but do not mediate the heart itself.	
Diagnosis	You may be prescribed:	
Diagnosis	• beta-blockers	
Diagnosis	• calcium channel blockers	
Diagnosis	• diuretics	
Diagnosis	• statins	
Diagnosis	• antiarrhythmics	
Diagnosis	• proton pump inhibitors	
Diagnosis	These help to regulate heart rhythm.	
Diagnosis	Heart transplant may be considered. This is very rare.	
Diagnosis	Lung transplant may be considered. This is very rare.	

Who We Are

SarcoidosisUK is the UK Sarcoidosis Charity. We're here to provide support, information and to fund research. The vast majority of our funds go towards researching a cure. We can support groups across the UK - please contact us for information on your nearest group.

How You Can Help:

Donate to fund research:
www.sarcoidosisuk.org/donate

Join our registry:
www.sarcoidosisuk.org/patient-registry

Thanks to:

Dr. J. Williams BSc, MSc, AgriMed, Consultant Cardiologist, Dr. A. Fawcett, Consultant Radiologist and Dr. M. Thillai, Consultant Chest Physician and Medical Sarcoidosis Unit, Royal Brompton Hospital, Dr. M. Wickremasinghe, Consultant Respiratory Physician and Dr. A. Varnava, Consultant Cardiology, Royal Brompton Hospital, London, UK.

UK: The Dutch Sarcoidosis Society

Contact Us:
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www.sarcoidosisuk.org
Charity number: 1263386

Twitter: @sarcoidosisuk
Facebook: facebook.com/groups/sarcoidosisuk
SarcoidosisUK

SARCOIDOSISUK NATIONAL QUIZ 2018

To celebrate Sarcoidosis Awareness Month this April, SarcoidosisUK are organising a special National Quiz to raise awareness and funds into our research for a cure. Come and join in the fun!

Quizzes will take place in the following 6 locations:

- ☑ **London** - The Horsehoe Inn - 26th April @ 7pm
- ☑ **Bristol** - Star and Dove - 28th April @ 7.30pm
- ☑ **South West** - St Austell Brewery Centre - 27th April @ 7pm
- ☑ **Perth** - Queens Hotel - 14th April @ 1pm
- ☑ **Norwich** - The Feathers Inn - 28th April @ 7pm
- ☑ **Nottingham** - The Deer's Leap - 28th April @ 7pm

Each quiz has been organised by the amazing volunteers who run our SarcoidosisUK Support Groups. Click the link below to find a quiz in your area.

Think you can help out with your local quiz? **Please get in touch.**

[FIND OUT MORE ABOUT THE QUIZ AND BUY TICKETS](#)

SUPPORT GROUPS' ROUND UP

We recorded a record monthly attendance in February 2018 with **67 attendees** group across 8 support group locations!

There are two new SarcoidosisUK Support Groups joining the network, see below. If you live nearby, why not go along to meet others and share your experiences. Our groups are very friendly and anyone is welcome.



Live in Hampshire or the West Sussex?

The first SarcoidosisUK Hampshire Support Group is meeting Cowplain Activity Centre (left), Waterlooville on 28th April.

Click here to find more details and RSVP.

Live in Cheshire or North Wales?

The first SarcoidosisUK Chester Support Group is meeting Hoole Community Centre (right), Chester on 29th April.

Click here to find more details and RSVP.



[SEE ALL UPCOMING MEETING DATES AND DETAILS](#)

SARCOIDOSISUK NURSE HELPLINE MAKES 300TH CALL

SarcoidosisUK Nurse Helpline - Caller Feedback

"The helpline was great. There is not much help or information except the internet, so speaking to someone who understands and can answer questions was brilliant, thanks."

"With this condition you can feel alone as its such a rare condition. It was so lovely to talk to some one who experienced the same condition and fully understood how you felt. She answered all my questions! A huge thank you!!!"

"I had a great experience with the SarcoidosisUK helpline and spoke to the most lovely woman. I felt like I could talk freely and I felt for the first time in 2 years that someone was listening to me. So helpful and caring."

Our very successful Nurse Helpline made it's 300th call this month!

The Helpline exists to provide anyone affected by sarcoidosis much needed information and support. Call are made each week by NHS nurses who have a superior knowledge and personal connection to sarcoidosis.

Callers have as much time as they need to talk through their situation with someone who understands what they're going through.

Thank you to our wonderful nurses!

[FIND OUT MORE AND SCHEDULE A CALL](#)

SarcoidosisUK relies on your support and donations! Please...

DONATE TO SARCOIDOSISUK

...to show your support and help us find a cure for sarcoidosis!

Please do get in touch anytime you would like to chat, we would love to hear from you.

**Best wishes,
SarcoidosisUK**

FOLLOW SARCOIDOSISUK:



Please get in touch, anytime, and we will get back to you:
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www.sarcoidosisuk.org

SarcoidosisUK is a registered charity | Charity Number 1063986

This and past editions of the SarcoidosisUK Newsletter can be downloaded in pdf format from [our website](#).

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