



Awareness

Sarcoidosis is a **rare and often confusing disease**. There is a problematic lack of understanding and awareness from the medical profession and the general public.

There are no official treatment guidelines for sarcoidosis in the UK. The resulting lack of awareness amongst GPs and other healthcare professionals unfortunately results in **frequent misdiagnosis and missed diagnoses**. Treatment standards and approaches can vary widely between practitioners and hospitals, meaning inconsistent and sometimes inadequate care.

Similarly, unawareness in the general public makes life much harder for patients who struggle to explain their '**invisible illness**'.

SarcoidosisUK is helping to alleviate these problems. Our goal is to make the public and healthcare professionals **much more aware of what sarcoidosis is** and how it affects the lives of patients. We raise awareness in a number of ways:

- distributing quality information in surgeries, hospitals and clinics across the UK.
- representing patients on advisory panels, task forces and conferences at regional, national and international levels.
- engaging with healthcare professionals and decision makers to improve quality of care.
- raising the profile of sarcoidosis in the news, online and on social media.

"I have joined lots of online support groups. The SarcoidosisUK Facebook Group is by far the most real, supportive and informative."

SarcoidosisUK Facebook Group Member



Research

Sarcoidosis is a condition that **does not receive sufficient attention** from pharmaceutical companies or medical researchers.

SarcoidosisUK may be small, but we are a leading investor in sarcoidosis research. Our goal is to continue to do this again and again, until we have found a cure.

We receive no government funding – our research would not be possible without your generous donations.

Visit our Website to Get Involved

Donate to fund our work

Sign up to the **SarcoidosisUK Newsletter**

Attend a **Support Group** in your area

Get involved in **Medical Research**

Join the **SarcoidosisUK Patient Council**

Contact Us

020 3389 7221

info@sarcoidosisuk.org

www.sarcoidosisuk.org

Facebook:

<https://www.facebook.com/uk.sarcoidosis>

Twitter:

@sarcoidosisuk

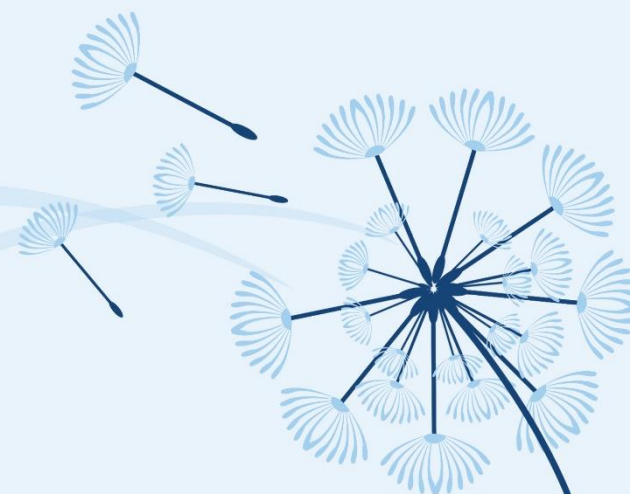
Charity Number: 1204750

DocRef: WHO3932

SarcoidosisUK

SarcoidosisUK

Who we are & what we do



SarcoidosisUK

What is Sarcoidosis?

Sarcoidosis (pronounced *sar-coy-do-sis*) is an inflammatory disease that can affect any organ in the body, most commonly the lungs and skin. **There is no known cause or cure.** Small clusters of inflammatory cells called ‘granulomas’ can prevent affected organs from working properly.

Sarcoidosis is a rare condition affecting around **1 in every 10,000 people in the UK** and about 1 million people worldwide. For some patients it goes into remission quietly, without causing significant damage. Others live with chronic, debilitating symptoms. Overall, sarcoidosis is fatal for 5% of patients. For those with the chronic condition, this figure is much higher.

For more information on different types of sarcoidosis, see SarcoidosisUK’s full range of Patient Information Leaflets. Read, download and order printed copies from our website.

Who We Are

SarcoidosisUK is a small charity working hard to improve the lives of sarcoidosis patients. We are entirely reliant on generous donations of time and money.

What We Do

Sarcoidosis suffers from lack of awareness, poor quality information, low levels of support and almost no research into finding a cure.

SarcoidosisUK work hard to change that through each of our four goals:



Information



Support



Awareness



Research



Information

Our goal is to provide **clear, quality and accurate information** about sarcoidosis to anyone affected, their carers and families, and to medical professionals. This is extremely important to us and something that we take very seriously.

All of our written information is produced with the help of **trusted medical experts** and is free for anyone to use, in print and online.

Our range of **Patient Information Leaflets** provide detailed information about different types of sarcoidosis. They are indispensable guides for patients, GPs, consultants and anyone else who wants to learn more.

Finding a sarcoidosis specialist can be difficult and confusing for patients and GPs. To help, we have created the UK’s first **Sarcoidosis Consultants Directory**. This database contains verified and updated details of sarcoidosis experts across the country.

Many sarcoidosis patients have questions about their condition, particularly when they are newly diagnosed. Our interactive online **FAQ page** covers a wide variety of topics and helps to answer some common queries.

We also provide up to date information on many other topics including nutrition, disability benefits, vaccines and travel advice.

“SarcoidosisUK’s medical information leaflets are a fantastic resource for both patients and medical professionals. I found them very useful and of great quality. Thank you!”

Dr Paul Minnis, Consultant Respiratory Physician, Northern Ireland



Support

SarcoidosisUK know that sarcoidosis patients often do not and cannot get the support they need or deserve.

SarcoidosisUK’s Support Services provide **vital practical and emotional** support for anyone affected by sarcoidosis. All of our support services are confidential and are provided free of charge.

Our goal is to ensure that anyone affected by sarcoidosis is able to speak to someone who cares about them, understands them and has the time to listen.

The **SarcoidosisUK Nurse Helpline** has talked to over 3,000 people affected by sarcoidosis, making calls all year round. Calls are made by NHS nurses who have personal and professional experience of sarcoidosis. The helpline has become a crucial service for those who need some additional reassurance and support to help understand their condition.

The **SarcoidosisUK Support Group** network spans the UK from Plymouth to Perth. Our aim is to connect patients together so they can help support each other in a safe environment. Many patients describe meeting someone else with sarcoidosis for the first time as “a life-changing experience”.

Our **Online Forums** are the perfect place for patients to give and receive support online.

“It was so reassuring and made me feel less isolated being able to talk to someone, who could help with my questions and give such good advice.”

SarcoidosisUK Nurse Helpline Caller