BTS ILD Registry Annual Report 2020: a summary of the UK Sarcoidosis Registry for the general public

Sarcoidosis is a disease where cells in the body clump together to make small lumps called ‘granulomas’. Granulomas can form in any organ of the body; however, the lungs are the most commonly affected organ (in over 90% of patients). Sarcoidosis is usually diagnosed between the ages of 20 and 50 years but it can also occur in those over 60. It is estimated that around 4,500 cases of sarcoidosis are diagnosed in the UK each year.

Some patients have no symptoms at all, and only know that they have sarcoidosis because it has been found incidentally when having tests for other conditions. Others have significant symptoms such as breathlessness, cough, fatigue or joint pain. While some people with symptoms recover, others gradually worsen over time.

Why is a registry needed?

Patient registries are collections of healthcare data on people living with a particular disease or condition. They aim to improve outcomes by making it possible to track treatment and care, and to link this to clinical outcomes of people living with the disease.

Sarcoidosis is a complicated condition which is sometimes hard to diagnose and treat. To improve understanding of sarcoidosis, it is important that researchers, people treating patients and people making decisions about healthcare policies can properly understand the experiences of people living with sarcoidosis.

Who is on the Registry?

Any patient diagnosed with sarcoidosis from 2013 onwards can be added to the Registry so long as they give their consent. As of 30th June 2020, a total of 547 patients with sarcoidosis were included on the Registry (an increase of 50 patients compared to October 2019). A total of 73 centres across the UK have so far been approved to participate in the Registry.

The British Thoracic Society (BTS) set up the BTS Interstitial Lung Disease (ILD) Registry in 2013. It currently covers two diseases: IPF and sarcoidosis. Information is submitted by hospitals on behalf of the patients they treat. The aim is to include as many people as possible in the Registry. BTS encourages hospitals and patients to agree to their data being collected so that the information in the Registry is as rich as possible.

What information is collected for the Registry?

In 2020, a review of the entire UK Sarcoidosis Registry dataset was conducted, which made it possible to analyse data trends over the past 7 years.

The Registry includes demographic data, including the patient’s gender, age, and comorbidities. This helps us to understand who is affected by sarcoidosis. From data collected over the past 7 years we know that:

- 58% of patients are male, and this has remained consistent over the lifetime of the Registry.
- The average age of patients presenting with sarcoidosis is 50 years. However, almost a quarter of patients present over the age of 60 years.
- Many patients with sarcoidosis have other medical comorbidities, with the two most common being high blood pressure (20%) and diabetes (15%).

The Registry also includes information on how patients are diagnosed with sarcoidosis. For example, we know that 96% of patients had at least one biopsy conducted as part of their investigations and that the most common biopsy sites were lung (29%), lymph nodes (25%) and skin (22%). The Registry also captures information on the most common blood test abnormalities and the patterns identified on high-resolution computed tomography (HRCT) imaging of the chest. We also know that most patients presenting with sarcoidosis either require no treatment (41%) or are managed with steroids (48%). These data help us to understand the full picture of how sarcoidosis is investigated and treated in the UK.

Hospitals can monitor their performance using Registry data and access data on their own patients. The Registry generates a local ‘dashboard’ every six months, which allows healthcare professionals to keep an eye on how the service is running. Information which identifies individual patients is only available to the submitting hospital (i.e. the team responsible for treating the patients).

BTS can analyse data for the whole country to help improve clinical care and when designing or recruiting patients to research trials. However, information which identifies individual patients cannot be seen in this national data.

Recent developments and plans for the future of the UK Sarcoidosis Registry

There have been several developments since the 2019 BTS ILD Registry Annual Report. In early 2020 BTS opened a ‘data access request process’, which allows external organisations to apply to BTS to access some of the Registry data to carry out research. It aims to benefit future patients by generating new insights into the diagnosis and treatment of sarcoidosis.

Our vision for the future of the UK Sarcoidosis Registry includes supporting clinical trial involvement. For the first time this year the BTS ILD Registry is being used to collect data for a large clinical trial of a different lung disease called idiopathic pulmonary fibrosis (IPF). It is our hope that the UK Sarcoidosis Registry will also be used to collect data for participants in clinical trials in the future.

Perhaps unsurprisingly, there has been a fall in the number of new sarcoidosis patients registered in 2020, as the respiratory community has turned its attention to manage patients with COVID-19 infection. This may limit the interpretation of recent data, but we hope, with the continued effort of everyone involved, that the Registry can go from strength to strength.

The future of the Registry is reliant on patients consenting to their information being used to help researchers, contribute to future planning of healthcare services and aiming to drive up standards of care for all patients with sarcoidosis. We hope that BTS can continue to build on the success of the Registry for many years to come.

Information for the public

This document has been prepared by Mr Steve Jones and Dr Wendy Funston, on behalf of the BTS ILD Registry Steering Group, as a brief summary of the content and key points from the BTS ILD Registry Annual Report 2020. If you have any queries about the report and your personal medical circumstances please discuss these with your health care professional.

The charity SarcoidosisUK supports patients who have been diagnosed with sarcoidosis: https://www.sarcoidosisuk.org/

The full report is available on the BTS website at: https://www.brit-thoracic.org.uk/quality-improvement/lung-disease-registries/.

The content of this document may be used by health care professionals in discussions with patients and/ or carers, but the source of the material must be acknowledged.

British Thoracic Society
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