



Sarcoidosis Patient Charter

As the Sarcoidosis Patient Advisory Group (SPAG) of the ELF (European Lung Foundation), we believe it is essential to raise awareness and understanding of the impact of sarcoidosis among patients, caregivers, healthcare professionals, policy makers, and the general public.

As European patient advocates, we are committed to contributing to the improvement of patient care and quality of life. That is why we have defined this joint strategy for the future.

Only together will we bring about a path of change. Let us walk this way in unity.

April 2022





Sarcoidosis Patient Charter



Sarcoidosis can be a short-term or a long-term disease. It has a variable course and can change in unpredictable ways. We do not know what causes sarcoidosis.

Sarcoidosis can affect almost any organ of your body and often involves many organs at the same time. In these organs, it causes inflammation which may lead to swelling of lymph nodes. It can cause different symptoms but may also be found by chance. Some people may experience symptoms that are specific to the organ affected, for example, cough and breathlessness when the lungs are affected and irregular heart rhythm when the heart is affected.

Others have very unspecific symptoms such as:

- fatigue,
- fever,
- loss of appetite,
- joint pain,
- muscle pain,
- cognitive difficulties (trouble understanding things), and
- weakness.

Despite being hard to test for these symptoms, they can be important parts of the clinical picture (1).

Besides “typical” organ-specific symptoms, these complaints can have a huge impact on patients’ lives and on their families (2). Sarcoidosis has similar symptoms to some other diseases. A doctor will need to rule out these other diseases. This makes the diagnosis of sarcoidosis and its care complex.

Once the diagnosis of sarcoidosis is made, it should be established which organs are involved and if their function is threatened. This will guide the doctor’s advice on whether or not treatment with medication is needed. We also know that in some patients symptoms disappear without treatment.

In Europe there are around 102.000 new sarcoidosis patients registered every year (20 in every 100.000 people). In the northern countries numbers are higher: Germany 28 people in every 100,000 and The Netherlands 22 people in every 100,000 (3, 4). A recent Swiss study confirms these statistics for the Scandinavian countries, they estimate an occurrence of 7 per 100.000 every year in Switzerland (5).

A clear quantitative insight is hard to get due to incomplete registers. There is an unknown number of cases, for instance when in the Netherlands the medical testing for compulsory enlisting of young male adults in the military was abolished the number of sarcoidosis patients declined dramatically.



As the **Sarcoidosis Patient Advisory Group** (SPAG) of ELF (European Lung Foundation) we are convinced that it is essential to raise the level of awareness and understanding among patients, caregivers, healthcare professionals, policymakers and the public about the impact of sarcoidosis.

We believe patients should be empowered to live with sarcoidosis without or with minimal burden only, optimising their interaction with professionals and improving their quality of life.

As patient advocates we feel obliged to contribute to improving patient care and quality of life. We defined the following **focus points**:

Diagnosis, treatment and care

- The broad nature of sarcoidosis requires a multidisciplinary (different areas of medicine) , and ideally an interdisciplinary (i.e. different areas of medicine working together) team of professionals as standard care.
- Medical and other professionals in these teams need to work closely together.
- The patient should have easy access to the team as well-rounded care will improve their quality of life.
- Patients should be involved in developing guidelines and carrying out research.

Reliable information and contact with peers

- Patients should have access to reliable information and patient organisations need professional support (based on national and international cooperation with medical associations) to produce this.
- Peer patient support should be organised in a way that patients, their families and friends have easy access. It should be culturally acceptable to all.

International and national cooperation

- As sarcoidosis can affect the whole body, is rare and in some patients a long-term disease, professionals, researchers, patient organisations and advocates must communicate effectively. Effective networking is a key factor that contributes to improving care and quality of life.
- Legislation and reimbursement schemes have to support both professionals and patients.



Call for Action:

As patient advocates the Sarcoidosis Patient Advisory Group (ELF), representing international patient organisations, we therefore strongly support the following Call for Action:

- Diagnosis and care for sarcoidosis patients should be carried out by multidisciplinary and ideally interdisciplinary teams, especially for those patients with multi-organ involvement.
- In these multidisciplinary and interdisciplinary teams a dedicated person should be responsible for co-ordination of care and communication with the patient.
- Patients and their healthcare teams making shared decisions is key for success.
- Multidisciplinary and interdisciplinary teams should work together in a network with a reference centre / centre of excellence World Association of Sarcoidosis and other Granulomatous Disorders (WASOG) at the core. It is essential for these networks to involve patient organisations and cooperate with European Reference Networks (ERNs) and other professional organisations such as the European Respiratory Society.
- Use of sustainable patient registries and biobanks to enable scientific research should be actively promoted.
- Patient organisations should provide reliable information about sarcoidosis that is backed by professionals.
- Patient organisations should be involved in research projects, prioritize research goals adding their experiences and helping to make results accessible.



References

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