

## Sarcoidosis Task Force patient involvement

The aim is to hold focus groups in the countries of the European Lung Foundation (ELF) patient advisory group (PAG) members. The focus groups would be led by the PAG patient organisation members and conducted with their patient members in their country. ELF will provide a detailed guide for the focus group leaders on how to conduct the focus group and what topics to cover.

The areas that the ERS/CHEST Task Force (ELF) intends to cover in its guidelines for healthcare professionals on sarcoidosis are **diagnosis, follow-up, and treatment**. To identify the key concerns of patients in these areas, the patient organisations in the ELF patient advisory group identified the 5 most important priorities/issues for patients in each of these three areas.

These patient concerns will help to identify the topics that should be discussed in the focus groups. The final schedule of topics to be covered in the focus groups will be agreed after discussion of this document by the patient advisory group and the TF chairs.

The patient organisations that submitted lists were:

- Association Suisse contre la Sarcoïdose (SSARV-AScS), Switzerland
- Asociación Nacional de Enfermos de Sarcoidosis (ANES), Spain
- Sarcoïdose Belangenvereniging Nederland (SBN), Netherlands
- Amici contro la Sarcoidosi Italia ONLUS (ACSI), Italy
- Deutsche Sarkoidosevereinigung (DSV), Germany
- Sarkoidosis Interessengemeinschaft (Sarkoidosis IG), Austria

Below is the combined list of patient concerns identified by the above patient groups. It shows the areas of concern expressed by four or more of the patient groups, with key aspects of each concern, as raised by patient groups, listed as bullet points. Some concerns applied to more than one of the areas and therefore have been listed under 'general' at the end.

Each patient organisation that independently expressed the concern is indicated by the country abbreviation, for example CH for Switzerland and IT for Italy.

**Please note:** You are welcome to send me feedback or questions on this document. However, as you are aware, we are still waiting for final confirmation of the ERS/CHEST contract (Memorandum of Understanding) before we can progress any further with this work. I thank you for your continued patience.

**Diagnosis** – *the process of getting a diagnosis and concerns around receiving the diagnosis*

### 1) Issues with fast and accurate diagnosis

- Full, correct diagnosis is necessary - need to address issues in diagnostic errors and incorrectness i.e. due to analysis and interpretation uncertainty by professionals.
- Clearer definition/better recognition of sarcoidosis symptoms to accelerate diagnosis and prevent incorrect diagnosis.
- Role of case histories in accelerating diagnosis and diagnostic accuracy – If health problems from childhood through adolescence to adulthood are recorded comprehensively, the first symptoms of sarcoidosis and susceptibility to infections will be recorded, helping to provide the information to support and accelerate diagnosis

- Time from first symptoms, to professional detection, and to confirmed diagnosis. Disparity in diagnosis times i.e. some people are diagnosed with minimal symptoms, whilst others have symptoms for years and can take years to receive a diagnosis.
- Who is/should be the professional to diagnose sarcoidosis i.e. generalists, respiratory specialists, sarcoidosis specialists etc.  
[CH, ESP, DE, AT, NL]

## 2) Diagnostic/monitoring tools

- Need for tests of acute and chronic sarcoidosis phases
- Tests for pulmonary and extra-pulmonary sarcoidosis, such as organ testing, biopsy, PET and CT scans, and endoscopy. The tests should be compatible with the clinical and/or radiological picture and histological evidence of non-caseating granulomas
- Include chitotriosidase exam and genetic profiling in the work up
- Tests to recognise diagnostic and prognostic markers of different types of sarcoidosis
- Use multiple tools in diagnosis and not only x-rays. Limit the use of x-rays
- Important to conduct multiple tests, but preferable to have them all conducted over a 2-day period instead of spread over lots of visits and this comprehensive work up should be performed by a specialist/specialist centre, as this is least disruptive to the patient's life and psychology.  
[CH, IT, DE, AT, NL]

**Follow-up** - *living with/managing your sarcoidosis, further visits with your doctor or other healthcare services*

### 1) Professional – professional communications

- Direct collaboration/communication between the sarcoidosis specialist and the patient's family doctor to enable the patient to continue visiting their local doctor for their medical queries - knowing that the doctor is aware of their sarcoidosis and how it may relate to other conditions etc.
- This communication should include a written record with information on the condition (remembering that the local doctor is not a specialist) and contact details,
- Two-way communication between the specialist team and the local doctor
- Needed for extra-pulmonary sarcoidosis and comorbidities – important for condition management
- Key workers to liaise between the different professionals involved, especially during diagnosis and initial treatment  
[CH, DE, AT, IT, NL]

### 2) Research and support networks

- Build an international network of specialist sarcoidosis teams and patient organisations to collaborate in research and improving clinical practice and support for patients. This network could include government representatives.
- This network should support doctors with less knowledge of sarcoidosis by providing information and answering clinical questions.
- To develop a sarcoidosis management charter to ask for endorsement and implementation by the EU and USA ministries of health so ensure that every patient can receive the same standard of treatment and care.

- Develop a registry for research, asking each patient if their test results and case histories can be included.
- Patient access to clinical trials.  
[IT, DE, AT, CH, NL]

### 3) Care pathway

- Define a pathway of care, from mapping the location of the sarcoidosis to treatment including psychological and quality of life factors
- A clear concept of rehabilitation is also needed in the care pathway
- The care should include consideration of the multi-organ stage and relapse history, and which specialist should lead in the diagnosis, treatment and monitoring of the condition
- Regular check-ups for diagnosis and monitoring of acute and chronic development, and staging, with guidance for healthcare professionals on follow up procedures  
[ IT, ESP, DE, NL]

### 4) Quality of life – impact of sarcoidosis on:

- Work/employment
- Social life/activities
- Relationships
- Finances
- Psychology (including stress, isolation, depression)  
[CH, ESP, AT, NL]

**Treatment** – *the medication or other forms of treatment that you have received for sarcoidosis, and any issues*

#### 1) Support

- Dietetics (especially for steroid side-effects).
- Physiotherapy and rehabilitation.
- Psychological – important in condition management and diagnosis (to help people cope with the condition), and with the side-effects of steroids). Therapies may include psycho-social counselling, cognitive behavioural therapy (CBT)
- Complementary/alternative therapies.
- **Informing patients and caregivers about patient organisations/support groups, especially as patient groups can** provide information and education to patients and their families/partners, including self-management support such as mindfulness and physical activity.  
[CH, ESP, DE, AT, NL]

#### 2) Treatments

- High number of drugs to treat/manage sarcoidosis, symptoms and comorbidities
- Treatment refusal and overmedication
- Anti-inflammatory painkiller (non-steroidal) versus corticosteroids
- Immunosuppressants (impact on immune system and developing other illness/conditions, people who do not respond to immunosuppressants)
- TNF alpha blockers

- Include infliximab as an 'in label' treatment and explore the evidence base for use of other biologic drugs
- Positive and negative side-effects, adverse reactions (including impacts of drugs for comorbidities)
- The role of 'off label' therapy for symptoms
- New drugs for sarcoidosis making it into clinical practice, including drugs to manage symptoms such as against persisting dyspnoea and fatigue
- Treatments for symptoms and comorbidities including: fatigue; breathlessness (dyspnoea), pain (correct muscular/osteoarticular/small fiber neuropathy pain management), and sleep issues (sleep pathology prevention, insomnia and obstructive sleep apnoea syndrome (OSAS/sleep apnoea).  
[CH, DE, AT, NL, IT]

## General

### 1) Professional awareness and education

- Knowledge and awareness of systemic sarcoidosis among doctors and education for medical students
- Depression and fear experienced by patients with a rare condition, as they fear the lack of knowledge of their doctors and information available to them
- Means of evaluating and monitoring performance of individuals/centres in sarcoidosis would be valuable
- Be aware/ responsive to varying patient needs and priorities at different stages of their condition.  
[IT, CH, ESP, DE, AT, NL]

### 2) Communication with patients

- Explain systemic sarcoidosis and organ impact on a diagram of the body, explain/show pictures of the diagnostic tools that will be used in the diagnosis.
- Clear definition of staging and communication to patient on what this means.
- Explanations on why the patient experiences joint pain despite radiological tests revealing nothing. Staging and prognosis. Relative effectiveness of treatment.
- Duration of treatment regimens and why.
- Encouragement by professionals for patients to self-report symptoms as important in follow-up/monitoring.
- Information on specialist centres
- Professionals need to be mindful that patients will attempt to self-diagnose and self-treat, and provide information and signposting to suitable websites and social media forums  
[CH, ESP, DE, AT, NL]

### 3) Multi-disciplinary team (MDT) approach

- Need to identify which organs have sarcoidosis i.e. pulmonary, extra-pulmonary. Involve a multi-disciplinary team with specialists in areas of all organs affected.
- Important not to forget any organ or tissue that can be affected – specialists should be involved, especially a rheumatologist i.e. to prevent/reduce damage to joints.
- Define a new multi-organ sarcoidosis staging approach so that the pathology and prognosis of sarcoidosis can be understood by the MDT and by the patient.

- Include psychological and social assessment in the MDT to ensure that the patient gets appropriate follow up/monitoring services following diagnosis.  
[CH, IT, DE, AT, NL]

#### 4) **Specialist centres**

- Importance of access to specialist centres in diagnosis (especially testing), treatment and for information/guidance for the patients' family doctor.
- Difference of opinion as to how much of the patient's diagnosis and management needs to be in a specialist centre.
- Specialist centres and networks required for sarcoidosis as vital to detect critical and serious organ involvements.  
[ESP, IT, DE, AT, NL]

#### 5) **Causes and risk factors :**

- Causes in developing sarcoidosis
- Genetic factors
- Impact of exposure to toxic substances
- Relationship between sarcoidosis and other conditions and aging
- Relationship between sarcoidosis and other chronic conditions and symptoms, such as fatigue, sleep issues, pain, stress and depression
- Impact of weakened immune system due to sarcoidosis on development of other illnesses and conditions [CH, DE, ESP, NL]