Snl ELF SPAG 2020-12-17 notes C. Knoet.

Concise overview ELF SPAG 2015 – 2020.

In September 2015 Courtney, on behalf of ELF, invited the sarcoidosis patient organisations in Europe and the FSR to meet at the ERS congress in Amsterdam. Primary reason was the intention of the ERS and CHEST to form a taskforce to update the Sarcoidosis Guideline dated 1999. Patient involvement was required. Between meetings the participants had an animated lunch at a restaurant called “The other side” and decided to join forces. Filippo, Bernd and Ginger were asked to represent us in the taskforce. The group, later known as the Sarcoidosis Patient Advisory Group (SPAG), was willing and able to act as a sounding board group.

In the following years the SPAG was meeting digital and once a year attended the ERS congress. At this moment the patient organisations from Austria, Germany, Italy, Serbia, Spain, Switzerland, The Netherlands, and the UK are represented. Also the FSR (Foundation for Sarcoidosis Research, USA) and Diane from Togo participate in our work. ELF, first in person of Courtney and since 2016 by Jeanette, supplies very much appreciated support. The group developed good working relationships and has proven the ability to enjoy each other’s presence in the so called “after hours” get-togethers.

We also use our attendance at the ERS congresses to network with the members of ERN-Lung and WASOG.

What did we, in the meantime, achieve ?

In 2016 / 2017 we conducted a survey on patient priorities resulting in an article / “research letter to the editor” of the European Respiratory Journal (ERJ) called **Sarcoidosis – patient treatment priorities** (2018). At the ERS congress in Paris Jeanette and Bob Baughmann presented the research letter at a **poster session**.

In the 2017 the ERS Taskforce started, after the decision to limit the focus on **treatment**. Recently the new **guideline** was delivered to the ERS. Soon to be published.

The ATS (American Thoracic Society) initiated a taskforce on a new **guideline** concerning the **diagnosis of sarcoidosis**. Both FSR and the SPAG (Filippo and Gian Luca) contributed. The guideline was published in 2020. Adaption to the EU practice and a lay version are in progress.

A third taskforce on sarcoidosis and pulmonary **hypertension i**s on its way.

In 2018 the **ELF Patient Priorities Project** on Sarcoidosis started. With Jeanette as driving force we delivered: a **website**, a **patient compass** (an interactive tool helping to prepare a patient for a consult with a doctor) and a **factsheet**. In progress are a **glossary** and a sarcoidosis version of the EURORDIS **patient journey**.

In April 2019 the SPAG was invited to the congress “Management of Sarcoidosis and ILD” in Belgrade. Besides meeting and working together, Jeanette and Chris gave a **presentation on patient priorities**, among others focussing on Quality of Life aspects.

This year on initiative of, among others Judson and Baughmann, FSR and 3 EU patient organisations assisted to / conducted a survey on **sarcoidosis and COVID -19**. The resulting article is published recently.

During the past period the advisory group members supported each other by mutual exchange of ideas, advice and materials. The SPAG members are grateful for the support we received from ELF. Special thanks to Jeanette who enabled us to become a vibrant group of patient advocates.