SARCOIDOSIS VASCULITIS AND DIFFUSE LUNG DISEASES 2023; 40 (4): e2023046 DOI: 10.36141/svdld.v40i4.15221

Could patients' association be considered a strategic resource?

Gianluca Ziosi[1], *Filippo Martone*[2]
[1]ACSI vice President, Bologna, Italy; [2]ACSI President, Bologna, Italy

To the editor,

As we all know, Patients' Associations are founded whenever people with same disease, look for information, support, or solutions to cover the unmet needs. Determination is their main skill. An example of this is represented by what happened in sarcoidosis world in the last 9 years.

In 2014 a European patients' association asked for renewal of guidelines in sarcoidosis, during Munich ERS congress. The taskforce was established, and ELF suggested that two patients' associations should joining the taskforce and in 2015 ERS, after a poll with associations present at that time, the German and the Italian ones were chosen. These two associations were part of the taskforce for guidelines in the subsequent years, invited by doctors involved in it. At the very beginning the patients' association were requested to define a survey, asking their members, to understand what their needs and vision were for the task force to meet. The result of this was a scientific article, cited many times in the following years. The decision to split the taskforce in two, diagnose and therapy, has not discouraged the associations that joined both. As part of the taskforces, we have pushed hard whenever things seemed to be stuck. Associations' stubbornness is well known.

Thanks to ELF (European Lung Foundation), various associations started to meet on a regular basis and reached the number of 11. This produced a constant sharing of experience and ideas that ELF reported back to ERS. An example of this has been the School of Sarcoidosis, organized by ERS last year.

During Covid time, practitioners asked associations to be part of an observational study to understand the Sars-Cov2 virus Impact on sarcoidosis patients. This number of people involved in this study was statistically consistent thanks to the work of all associations involved.

The role of associations in observational studies is a determining factor for two reasons, number of people and speed in retrieving information. 11 different associations deeply rooted in their own countries could work in parallel, dramatically increasing results in quality and quantity.

Participation to relevant congress, like ERS ones, greatly benefit associations giving them the opportunity to have a full picture of sarcoidosis universe, dealing with professionals focused on it and exchanging insight. Furthermore, dealing with experts, give associations the capability to organize in their own country events to increase awareness and educating local medical doctors, developing their knowledge of sarcoidosis.

Moreover, patients' associations are supporting their local expert to be part of ERN as well as other international projects. By that, associations constant work on different level has given support to ERN-Sarcoidosis creation, the first single disease specific ERN in ERN-Lung.

What is missing? Now Europe is larger than ever, more than 30 countries are part of it but, unfortunately only 10 countries have expressed a patients'

Received: 18 August 2023
Accepted: 18 September 2023
Correspondence: Gianluca Ziosi, ACSI vice President
Via Alcide de Gasperi, 5/7
Monte San Pietro (BO), 40050 Italy
E-mail: gianluca.ziosi@sarcoidosi.org

association. It is really important to increase this number as we will all benefit from more associations working together. Medical expert should be active part in proposing the formation of these entities when not present in specific countries. Currently, the countries represented are Netherlands, Germany, Belgium, United Kingdom, Ireland, Italy, Spain, Switzerland, Serbia, and Austria

So, getting back to the question, could Patients Associations be considered a strategic resource? My answer is obviously yes but as vice president of a Patients' Association I am not neutral, nevertheless we need to increase the number of countries where there are Patients Associations.

Conflict of Interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article