

Sarcoidosis patient groups

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Challenges faced by sarcoidosis patients

Sarcoidosis patients face many complex challenges. A high percentage of patients experience a difficult diagnosis or a misdiagnosis. There have even been reports of a patient who presented symptoms at the age of 12 yrs, but did not receive a proper diagnosis of sarcoidosis until the age of 40 yrs. Other patients have received a misdiagnosis of cancer or have been accused of imagining their symptoms and referred to psychiatrists.

In the treatment of their disease, many patients are prescribed prednisone. Prednisone has many adverse side-effects, including weight gain, diabetes, high blood pressure, mood swings, depression, difficulty sleeping at night, heartburn, acne, thinning of the skin and bones, cataracts, glaucoma and adrenal gland insufficiency. Patients struggle with the side-effects of weight gain, mood swings and depression as these symptoms adversely affect their quality of life (QoL). Many patients are faced with the difficult decision of whether to endure the side-effects of the medication or the symptoms of the disease.

Fatigue is a huge QoL issue. A major percentage of sarcoidosis patients experience severe fatigue which impairs their ability to function at their normal level. Another QoL issue that patients experience is that they look completely healthy. Many times when patients complain of their symptoms to family, friends and colleagues they are not taken seriously or are accused of making up their symptoms. Also, others do not understand why patients are not able to perform work or participate in social activities as they previously did prior to their illness as they "look fine".

Patient groups and their importance

Sarcoidosis patients should have a central place in the related medical care. To improve this care, patient societies were started. In Europe, the first patient society was founded in The Netherlands in 1978. Thereafter, many other countries followed this initiative (see Appendix). In the USA, sarcoidosis patient groups were first formed in 1991. Additionally, in 2001, a European (and later a Mondial) society, the European Association of Patients Organisations of Sarcoidosis and other Granulomatous Disorders (EPOS), was founded by the Deutsche Sarkoidose-Vereinigung (Germany), the Sarkoidose Belangenvereniging Nederland (The Netherlands), the Sarcoidosis and Interstitial Lung Association (UK), and the Schweizerische Sarkoidose-Vereinigung (Switzerland). EPOS was founded as the international umbrella under which all national patients' organisations will be represented. EPOS has clearly marked targets and ideals. These include active participation in the foundation of (new) national organisations and

also to stimulate international research and provide a forum for the exchange of ideas, experiences and expertise. The priority remains the provision of adequate information for patients and all others involved, in the broadest sense. The suffering of the long-term sarcoidosis patient must be recognised as unsatisfactory. Not only is the cause unknown but a medical cure remains undiscovered. In order to help these patients and those who aim to help them, EPOS was brought into being.

All societies have members suffering from sarcoidosis, as well as active supporters. The aims of all these societies are to provide a forum and a network for those having similar experiences and their partners, to provide appropriate and up-to-date information and organise regional, national and international meetings for patients and physicians. It is of benefit to patients to communicate with others who have the same symptoms as it confirms that those symptoms are real and not just in their minds. Talking to other patients lends credibility to patients and their families that others are experiencing the same frustrations. Patients are also provided with the opportunity to discuss their diagnosis and treatment plans that have been effective for them.

Programmes and services offered by patient groups

Many patient groups host educational conferences, provide videos, newsletters, websites and literature that provide invaluable information to enable patients to understand and manage their disease.

Patient organisations have also developed and implemented programmes to promote the public's awareness about sarcoidosis. Increased awareness also increases the probability of better diagnosis by a physician.

Some sarcoidosis groups engage in research initiatives to identify the cause and cure for the disease, and to improve diagnosis, prevention and treatment. Patient websites and hotlines are available to help patients locate physicians knowledgeable of the disease. The organisations have their own advice boards with various members, including psychologists, lawyers, insurance physicians, and physiotherapists, to ensure that the information provided is as broad as possible. Many groups are involved in advocacy efforts to foster support for sarcoidosis initiatives from the local, state and federal entities.

Another important task of the societies is to promote research related to sarcoidosis.

National and international collaborative efforts

For several years there has been cooperation between the sarcoidosis patient societies within Europe, as well as between Europe, the USA and Japan. These cooperations will be explored in the near future. To promote the interest of sarcoidosis patients in the best way possible, delegates of various patient societies became a member of the World Association of Sarcoidosis and Other Granulomatous Disorders (WASOG) and participated in the international congresses. Some of the sarcoidosis groups have collaborated to host an educational patient conference in conjunction with the WASOG in Denver, USA (June 12, 2005).

Sarcoidosis patient groups have successfully joined forces to collaborate on projects that have proven beneficial to patients. As a result of these efforts in the USA, the National Institutes of Health has formed a Trans-Institute Working Group to develop a comprehensive research agenda for sarcoidosis. This is a phenomenal step as sarcoidosis affects so many different organs and systems within the body. Furthermore, sarcoidosis

patient societies try to stimulate the interest of researchers to design studies related to this disease. For example, an award is given to a young researcher every year by the Dutch Sarcoidosis Society to a promising research project in The Netherlands dedicated to sarcoidosis.

In the USA, the Foundation for Sarcoidosis Research (FSR) is a nonprofit organisation dedicated to improving care for sarcoidosis patients and finding a cure for this disease. Since its establishment in 2000, the FSR has worked diligently to provide resources to thousands of patients, their families and their physicians, and has funded several domestic and international research efforts. FSR has a long history of educating consumers and their healthcare professionals, as well as providing direct support to critically needed research. FSR's annual awareness campaign the "Kick In to Stop Sarcoidosis" (KISSTM) reaches hundreds of thousands of people with a combination of education events, printed articles, televised health reports and public service announcements. The FSR board of directors feels strongly that the causes of this disease, and ultimately a cure, will be uncovered through rigorous and extensive scientific research. The FSR's Research Grants Program is the nation's first privately funded programme for sarcoidosis research. They support young researchers by providing young investigator's awards for excellence in sarcoidosis research at the latest American Thoracic Society and WASOG meetings. Furthermore, they stimulate research by offering partnership grants for sarcoidosis research. It is vital that the FSR maintain a high level of support for sarcoidosis patients and expand the type and availability of provided services. In the coming months, this would include plans for new patient and professional education initiatives; moreover, the FSR intends to continue its efforts to fund research to find better treatments and hopefully, someday, a cure for this devastating disease.

In summary, sarcoidosis patient groups play an integral role in patient care and are a driving force in the quality of the science and research that will ultimately identify the cause and find a cure for this complex and debilitating disease.