

## What is FESCA?

FESCA is the Federation of European Scleroderma Associations, a unique link among European scleroderma support groups throughout the European Union. Founded in February 2007, FESCA currently has 16 member groups and includes patient associations from Belgium, Cyprus, Denmark, Germany, France, Hungary, Ireland, Italy, the Netherlands, Portugal, Spain, Switzerland, and the United Kingdom.

Our mission is to represent the interests of those who have scleroderma, also known as systemic sclerosis.

Our aim is to promote the advancement of knowledge, research, and information in the field of scleroderma within medical, governmental, and social arenas, and to increase awareness of the disease among the general public.

## What is Scleroderma?

Scleroderma is a disease of the immune system, blood vessels, and connective

tissue. It is an uncommon and complex autoimmune disease of unknown origin, characterized by fibrosis of the skin and of the internal organs, and by damaging vascular changes.

There is no wonder drug for scleroderma, but medications for its specific symptoms can stop its progress and improve its effect and outcome. While Raynaud's, a circulation disorder, is generally the first symptom of the systemic types of scleroderma, it is difficult to diagnose due to the variability of its symptoms and progress. Medications are too numerous to list here, but include creams, pills and infusions. Physical, social, and psychological support are also helpful.

## The FESCA Vision

The FESCA vision is one of a world in which scleroderma is recognised as an important disease, and those with the disease do not feel so isolated. We believe that people with scleroderma must have equal access to successful treatments, and medical practitioners must have better knowledge.

## FESCA and EUSTAR

FESCA's goal is to make scleroderma well-known, and, in collaboration with doctors, to secure for those who have it the best treatments, care, and ultimately a cure. To accomplish this, we are working closely with EUSTAR, an association of doctors dedicated to researching the causes and treatments of scleroderma. Together, FESCA and EUSTAR are actively promoting knowledge and education, creating a growing database of information.

As national associations share ideas and projects, FESCA is able to educate Europe and its medical community about scleroderma, as well as to foster action, debate, and research. Action takes a variety of forms, such as seminars, workshops, publications, and information campaigns. We have been involved in developing the EULAR/EUSTAR Recommendations for the Treatment of Systemic Sclerosis. We plan now to play a significant part in VEDOS (Very Early Diagnosis of Scleroderma), a project led by EUSTAR.