



Federation of European Scleroderma Associations

International Non Profit Association

Reg.n° FESCA aisbl. 889.943.920

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June 29th is World Scleroderma Day

## Patients with Scleroderma are much more than their disease

FESCA, the Federation of European Scleroderma Associations, is ready to celebrate another World Scleroderma Day with a campaign to raise awareness of Scleroderma, also known as Systemic Sclerosis.

Scleroderma is a rare, chronic autoimmune rheumatic disease that affects the body by hardening connective tissue. Skin and internal organs can be damaged by this illness. It is life threatening and currently there is no cure. However, successful treatments are available for individual organs.

Early diagnosis is vital. If you experience reflux, have swollen puffy fingers and your hands change colour, don't delay and contact your doctor!

It can appear at any age, but it is more frequent in women between 30 and 50 years old.

“The lack of awareness and understanding across healthcare professionals has led to delayed diagnosis, which can have serious and potentially life-threatening consequences for people with Scleroderma. It is vital that people with Scleroderma are identified as early as possible, so they can receive the appropriate treatment and care”, said Sue Farrington, President of FESCA.

The theme of FESCA's awareness campaign of 2021 is recognising that the person with Scleroderma is so much more than the disease.

The slogan is “I AM MY PASSION NOT MY DISEASE! Scleroderma and COVID 19 will not take my smile!”

While it is vital that we increase knowledge about the condition, it is also important that we treat and understand the person not just the disease. The aim is to value as much as possible what each patient does in their life by showing their passion, by showing what makes them smile, fight, and overcome the disease.

“This is an illness that has necessarily guided their journey differently, but it is essential to value and focus on what is positive and to detach yourself from what cannot be done and always from a positive, constructive and even overcoming perspective,” said Helena Gaspar, patient from Portugal.

A video, and other graphic materials are part of our campaign and will be shared by 26 member associations in 20 countries to raise public awareness and understanding among national and international authorities and institutions.

INTERNATIONAL NON PROFIT ASSOCIATION

**Federation of European Scleroderma Associations (FESCA aisbl.)**

Registered address: **Rue du Pont à Rieu 13 i, 7500 Saint Maur, BELGIUM**

**26 Member Associations (20 countries):**

**Austria** : Selbsthilfe e.V. **Belgium**: Association des Patients Sclérodermiques de Belgique asbl; Chronisch Inflammatoire Bindweefselziekten-Liga vzw.

**Croatia**: Hrvatska Udruga Oboljelih od Sklerodermije. **Cyprus**: Αντιρευματικός Σύνδεσμος Κύπρου. **Czech Republic**: Revma Liga (CZELAR).

**Denmark**: Sklerodermiforeningen. **Finland**: Suomen Sklerodermayhdistys ry. **France**: Association des Sclérodermiques de France.

**Germany**: Sklerodermie Selbsthilfe e.V.; Sklerodermie Liga e.V. **Hungary**: Országos Scleroderma Közhasznú Egyesület.

**Israel**: INBAR **Italy**: AILS; APMAR; ASSMaF; GILS. **Netherlands**: N.V.L.E. **Norway**: Norsk Revmatikerforbund. **Portugal**: Associação Portuguesa de Doentes com Esclerodermia; Portuguese League Against Rheumatic Diseases. **Romania**: Asociația Pacienților cu Sclerodermie din România. **Spain**: Asociación Española de Esclerodermia. **Sweden**: Reumatikerförbundet. **Switzerland**: sclerodermie.ch. **United Kingdom**: Scleroderma and Raynaud's UK