

The Federation of European
Scleroderma Associations aisbl.
welcomes you to the

Second World Scleroderma Congress

Madrid, Feb 2-4, 2012





FESCA IVZW

Federation of European Scleroderma Associations

The Role of FESCA aisbl.

Our role is to support and link national scleroderma patient organisations to provide the strength found in unity, pooling our resources to share best practices and practical strategies.



FESCA – Organisation

- Founded in 2007, FESCA is open to all national scleroderma patient support organisations in Europe
- In Jan 2012, we have 21 member organisations from 16 countries, and two more countries joining up
- Each country has two votes
- The number of member organisations from any country may not exceed two
- The Council is formed by a delegate from each member organisation
- FESCA is in useful contact with other countries around the world: Friends of FESCA



FESCA aisbl. Council

- Belgium-French
- Belgium-Dutch
- Cyprus
- Denmark
- France
- Germany
- Hungary
- Ireland
- Italy-GILS
- Italy-AILS, APMAR, ASSMAF

- Netherlands
- Poland
- Portugal
- Spain
- Switzerland
- UK-SSc Soc
- UK-RSA

Finland and Norway plan
to join



Board of FESCA Council

An elected, volunteer board of officers, drawn from national societies to direct the umbrella group :

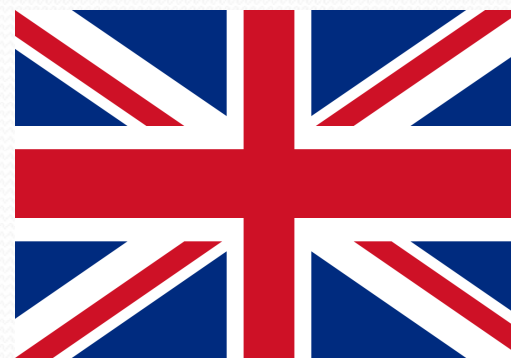
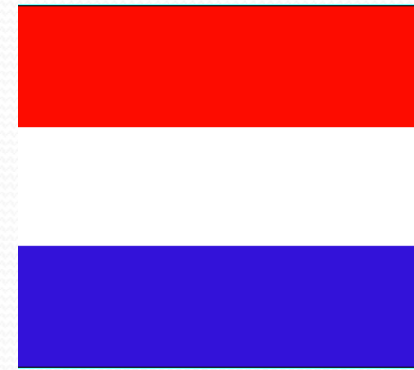
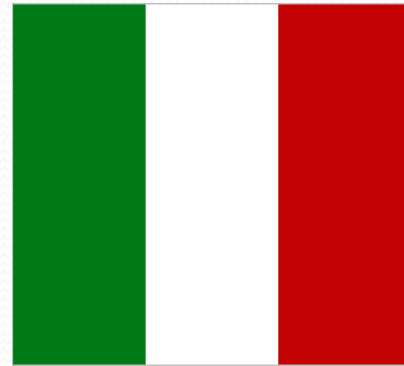
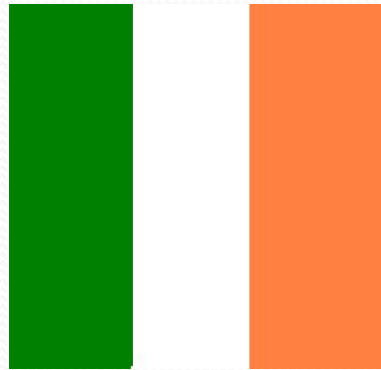
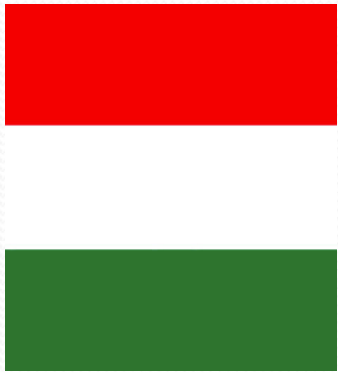
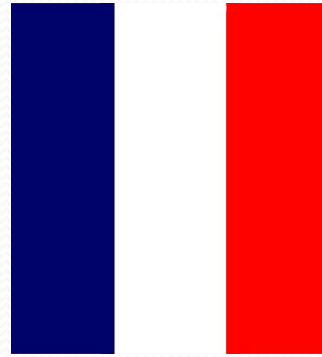
President : Ann Tyrrell Kennedy (Ireland)

Vice-President : Beata Garay-Toth (Hungary)

Treasurer : Despo Charalambous-Demetriou
(Greece)

Secretary: Catherine Van den Bosch (Belgium)





FESCA aisbl.

“The aim of the Federation is to support people with scleroderma by promoting the advancement of knowledge, research, and information in the field within medical, governmental, and social arenas, and by increasing awareness of the disease among the general public.”

Article 5, FESCA Constitution



FESCA aisbl. – Our Aims

- We strive to increase awareness of SSc--low in government and the general public, and even in medical professions
- We share information with new young associations that support those with SSc throughout Europe
- We work to increase understanding of medical and sociological aspects of the disease by speaking out, and through our website and publications
- We offer mutual support
- We increase communication between doctors and sufferers
- We are a beginning point for hope



Systemic sclerosis (SSc)

- A rare connective tissue disease –its epidemiology and causes are not even known
- Multi-system, chronic, incurable, and unpredictable
- Not inherited, racial, infectious, or contagious
- Affects the musculoskeletal & vascular systems, skin, and internal organs—heart, lung, kidneys and the gastrointestinal tract
- Found predominately in women
- Huge number of “minor” symptoms
- Overload of symptoms even for doctors treating the disease

Specialists visited by a SSc patient



Scleroderma

Has a major impact on:

- Work potential
- Financial situation
- Life-Partnerships
- Social relationships
- Confidence in every area of life

Can be:

- Life-threatening, with the highest mortality rate of any of the connective tissue diseases
- Life-limiting and isolating, turning people into recluses

National groups

- Support patients on a daily basis
- Offer counselling
- Provide info on treatments & side-effects
- Give help with psychosocial aspects
- Offer advice on complementary therapies
- Provide advocacy throughout the medical odyssey
- Provide help through maze of paperwork

What do we do?

- Act as a central clearing house for queries and those who don't know where to begin
- Collect and distribute information on all aspects of SSc
- Help doctors to understand those they treat
- Help national societies to understand what is available
- Foster excellence in research to improve treatment and patient care
- Encourage participation in research projects and trials
- Encourage surveys and research projects and provide a patient base for their success

We also:

- Seek representation in any organisation that might help our members down the line
- Work with groups such as Eurordis and EULAR to increase the help available to those with SSc
- Work for parity of treatment and care and drug availability throughout the EU
- Spread information about treatment breakthroughs in other parts of the world
- Interconnect—put people in touch with each other



Paul Klee, Kettledrummer 1940, 270 (coloured paste on paper on cardboard), 34.6 x 21.2 cm, Zentrum Paul Klee, Bern,

June 29 World Scleroderma Day

Scleroderma: More Than Skin Deep

World Scleroderma Day

- 29th June annual awareness day event
- Paul Klee memorial
- Events throughout world in celebration
- Theme in 2011 “So Rare”
- Goal: Improve access to successful treatments & provide equal and consistent care across the globe
- Goal: Make those with scleroderma feel less isolated

On SSc Awareness Day...

In addition to publicity campaigns in all countries,

- In Spain, a mobile van
- In Hungary, the first SSc conference
- In France, two SSc conferences and a TV commercial
- In Holland, a SSc conference
- In Ireland, a launch event with the Minister for Health
- In Denmark, a blitz on libraries and clinics
- In Cyprus, a conference and a press event
-and more

We share our literature



We share our energies



We combine
our strengths

