

# FESCA NEWS

News from the Federation of European Scleroderma Associations, Summer 2015

## FESCA holds event in EU Parliament, June 2015

To celebrate World Scleroderma Day 2015, the Federation of European Scleroderma Associations (FESCA aisbl.) held the European **Parliamentary event “Unveiling Scleroderma: Hidden Truth” on June 30 in Brussels.**



All MEPs were invited to this EU Parliament meeting to listen as the invited experts spoke about the quality of care available for scleroderma patients across Europe.

Hosted by James Carver MEP, who lost his wife to scleroderma in 2009, the event provided a unique forum for patients, physicians, and politicians to share their stories and understanding.

Key medical professionals from across Europe highlighted the importance of early diagnosis, sufficient investment in research and specialist centres, and equity of care. The presentations on these topics included insightful talks from Professor Denton (UK), Professor Distler (Switzerland), Dr. Posada De la Paz (Spain) and Professor Van den Hoogen (Netherlands). These key rheumatologists spoke of how although the effects of scleroderma can be devastating, proper treatment and management can enable people with scleroderma to lead full and rewarding lives.

The MEPs attending were also privileged to hear from a number of patients themselves, from Denmark, the Netherlands, Hungary and the UK, who shared with the audience inspiring stories of their difficult journeys with scleroderma. EULAR representative **Nele Caeyers spoke of the support that is given to FESCA by the EU’s major rheumatology organisation.**

World Scleroderma Day 2015 was developed by FESCA to raise awareness of the 2.5 million people currently diagnosed worldwide who live with this rare and under-recognised disease. Its success is due to the commitment of all the national patient

support and advocacy groups who form part of the umbrella organisation.

**Ann Tyrrell Kennedy, President of FESCA, said “World Scleroderma Day was a huge success and it has been encouraging to see awareness of scleroderma gaining momentum across Europe. It’s so important that we make the journey to a diagnosis as short as possible, and having the support of politicians and physicians alongside patient groups is a really important step to improving millions of lives across the world.”**

For more information please contact [www.fesca-scleroderma.eu](http://www.fesca-scleroderma.eu).



*Joep Welling, Netherlands, and Annelise Roennow, Denmark, patient speakers*



*Patient and medical speakers from across Europe*



*Beata Garay-Toth, Hungary, patient speaker*



*Nicola Whitehill, UK, patient speaker*



## EULAR Rome Congress, June 2015

From 9<sup>th</sup>-13<sup>th</sup> June 2015, we attended the EULAR ROME congress where FESCA held a stand to inform delegates about FESCA and its member organisations. Kim Fligelstone and Ann Tyrrell Kennedy additionally attended the SCLERO-ID project meetings along with many patients (more details below). We were also pleased to see four articles on SSc published in the EULAR congress news, more than we have seen before. You can download a copy of EULAR Congress News (Edition 12/13 June) from the EULAR congress news website: <http://www.eularcongressnews.com/> . The articles were entitled:

Page one: Systemic Sclerosis Gut Microbiota Described For the First Time: Dr. Elizabeth Volkmann, rheumatologist and clinical instructor, University of California

Page seventeen: New jSSc Registry Seeks Better Knowledge, Therapies: Dr. Ivan Foeldvari, Director of the Hamburg Centre for Pediatric and Adolescent Rheumatology

Page nineteen: Chronic Disease-Related Fatigue Questionnaire Tested in SSc: Dr. Kwakkenbos, post-doctoral fellow, Department of Psychiatry at McGill University, Montreal

Page twenty-one: Immune Complexes Implicated in SSc Pathogenesis: Dr. Cecilia Chighizola, Postdoctoral Fellow, University of Milan



*Photo left: Teresa Pizzetti, Ann Kennedy, and Grazia Tassini at the FESCA stand*



*Photo right: Sclero-ID group*

## EULAR Sclero-ID

On the 9<sup>th</sup> and 10<sup>th</sup> June people with scleroderma (SSc) attended the first Sclero-ID meeting held in Rome. Some traveled to Rome and others took part by webinar/teleconference. Medical experts were also present but asked to sit on their hands and say as little as possible because the most important contributions were from those who have first-hand experience of living with the impact of scleroderma.

After introductions the program and purpose of the project was discussed at length, which is to develop and validate a brief, disease-specific, patient-driven, disease impact score for scientific and clinical use in patients with SSc. By the end of the first day we had sixty-six health issues which have to eventually be broken down to a maximum of fifteen. The moderator and medical experts worked long into the night to put together any over-lapping issues before the work began to see which of the others could **be broken down further. You probably won't be surprised to hear this proved impossible due to the** complexity of the disease; by the end of day two, I think we were down to twenty-three. This is a EULAR project and strict guidelines have to be met; thankfully we have a very experienced moderator in Turid Heiberg to guide us through the identification and grouping of the health dimensions.

The next step is to establish a web-based survey that will be sent randomly to people with SSc who will be asked to rank/prioritise according to their own experience. This is the beginning phase of the scleroderma disease impact score and the next face to face and telecon meeting will take place in June 2016. Meanwhile if you receive a survey, which should be around September, please complete it as your input will be invaluable to make this project a success.

## What is scleroderma?

Scleroderma (SSc) is a chronic and incurable, usually progressive, disease of the immune system, blood vessels, and connective tissue. It is neither contagious nor infectious, not inherited, and, while it is rare in children, it is four times as likely to affect women as men. It can develop at any age, although onset is most frequent between 25 and 55. Raynaud's is most commonly the first symptom. No causes have as yet been identified. While it is not genetic, there may be a slight predisposition in families with a history of rheumatic diseases. SSc has many manifestations, including thickening and hardening of the skin, and it can affect all organs except for the brain. It is extremely hard to diagnose as it presents in different combinations of symptoms in different people, at variable rates. It has been divided into several different disease subsets. No systemic cure is available, but treatments for individual organs and symptoms are effective and can restore quality of life. One of the chief causes of death in scleroderma (systemic scleroderma) is pulmonary arterial hypertension (PAH).

## How many people have scleroderma?

A rare disease is defined as having an incidence of no more than 5 per 10,000 people. SSc has an incidence, according to data recently gathered in the UK, of 1 in 10,000 people. But its epidemiology has never been properly studied, and while it is expected to be equally prevalent in all countries, the estimates made by each country vary. It is generally considered true that 10% of any national group will suffer from Raynaud's, and of these 2-7% will have SSc. In the USA, it is estimated that there are 300,000 people with SSc in a population of 306 million.

## Member Organisations

### Belgium

League for Chronic Inflammatory  
Connective Tissue Diseases  
<http://www.cibliga.be>  
[secretariaat@cibliga.be](mailto:secretariaat@cibliga.be)

Patients Association for Scleroderma (APSB)  
<http://www.sclerodermie.be>  
[sclerodermie@clair.be](mailto:sclerodermie@clair.be)

### Croatia

The Croatian Society For Patients With  
Scleroderma (CSPS)  
<http://www.huos.hr>  
[huos@huos.hr](mailto:huos@huos.hr)

### Cyprus

Cyprus League Against Rheumatism  
<http://www.rheumatism.org.cy>  
[cyplar@cytanet.com.cy](mailto:cyplar@cytanet.com.cy)

### Denmark

Danish Scleroderma & Raynaud's Association  
<http://www.sklerodermi.dk>  
[info@sklerodermi.dk](mailto:info@sklerodermi.dk)

### Finland

Finnish Scleroderma Association  
<http://244846.edicypages.com>  
[marjo.makela@ebaana.net](mailto:marjo.makela@ebaana.net)

### France

French Scleroderma Patient Organization  
<http://www.association-sclerodermie.fr>  
[info@association-sclerodermie.fr](mailto:info@association-sclerodermie.fr)

### Hungary

Hungarian Scleroderma Association (Országos  
Scleroderma Közhasznú Egyesület)  
<http://www.scleroderma.hu>  
[scleroderma@freemail.hu](mailto:scleroderma@freemail.hu)

### Ireland

Raynaud's & Scleroderma, Ireland  
<http://www.irishraynauds.com>  
[info@irishraynauds.com](mailto:info@irishraynauds.com)

### Italy

Association for the Study of Systemic  
Sclerosis and Fibrosanti Diseases  
<http://www.assmaf.org>  
[info@assmaf.org](mailto:info@assmaf.org)

Italian Association to Scleroderma Fight  
<http://www.ails.it>  
[ails-an@libero.it](mailto:ails-an@libero.it)

Italian Groupe for the Struggle  
to the Scleroderma  
<http://www.sclerodermia.net>  
[gils@sclerodermia.net](mailto:gils@sclerodermia.net)

Pugliese Association Arthritis Patients  
<http://www.apmar.it>  
[info@apmar.it](mailto:info@apmar.it)

### Germany

Patient Organization for Scleroderma  
<http://www.sklerodermie-sh.de>  
[sklerodermie@t-online.de](mailto:sklerodermie@t-online.de)

### Norway

The Norwegian Rheumatic Organisation  
<http://www.sklerodermi.no>  
[sklerodermi@revmatiker.org](mailto:sklerodermi@revmatiker.org)

### Poland

Pro Rheumate – Group of Scleroderma Patients  
<http://www.twardzina.pl>  
[bealew23@wp.pl](mailto:bealew23@wp.pl)

## Federation of European Scleroderma Associations (FESCA )

*International Non-Profit Association*

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**Website:** [www.fesca-scleroderma.eu](http://www.fesca-scleroderma.eu)

### Registered address:

**FESCA aisbl., Le Versailles  
20/32 Avenue des États Unis  
7500 TOURNAI, Belgium**

**President:** Ann Tyrell Kennedy, Ireland

**Vice-President:** Beata Garay-Toth, Hungary

**Secretary:** Alexandra Portales, Spain

**Treasurer:** Despo Charalambous Demetriou, Cyprus

### Counsellors:

Kim Fligelstone, U.K.

Nadine Paciotti, Switzerland

Annelise Rønnow, Denmark

Joep Welling, Netherlands

**Newsletter Editor:** Susie Hoare, U.K.

DISCLAIMER: FESCA aisbl in no way endorses any of the medications or treatments reported in this newsletter. Information is provided only in a good-faith effort to share news. We strongly advise that you consult your doctor regarding any medications or treatments of interest to you, since every person reacts differently.

### Portugal

The Portuguese League Against  
Rheumatic Diseases  
<http://www.lpcdr.org.pt>  
[lpcdr@lpcdr.org.pt](mailto:lpcdr@lpcdr.org.pt)

### Romania

The Romanian Association of  
Scleroderma Patients (APSR)  
<http://www.sclerodermie.ro/>  
[contact@sclerodermie.ro](mailto:contact@sclerodermie.ro)

### Spain

Spanish Scleroderma Association  
<http://www.esclerodermia.org>  
[a.e.esclerodermia@wanadoo.es](mailto:a.e.esclerodermia@wanadoo.es)

### Sweden

The Swedish Rheumatism Association  
<http://www.reumatikerforbundet.org>  
[info@reumatikerforbundet.org](mailto:info@reumatikerforbundet.org)

### Switzerland

Swiss Association of Scleroderma Patients  
<http://www.sclerodermie.ch>  
[info@sclerodermie.ch](mailto:info@sclerodermie.ch)

### The Netherlands

N.V.L.E. Patient Organization for Lupus,  
Scleroderma and MCTD  
<http://www.nvle.org>  
[info@nvle.org](mailto:info@nvle.org)

### U.K.

Raynaud's & Scleroderma  
Association (RSA)  
<http://www.raynauds.org.uk>  
[info@raynauds.org.uk](mailto:info@raynauds.org.uk)

The Scleroderma Society  
<http://www.sclerodermasociety.co.uk>  
[info@sclerodermasociety.co.uk](mailto:info@sclerodermasociety.co.uk)