



FESCA NEWS 1st edition, February 2009

Welcome to the first edition of FESCA NEWS!

In this edition we present FESCA to you, we explain the connection with EULAR and EUSTAR, and of course we discuss the first EU Scleroderma Day on June 29th 2009.

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 18 member associations and includes patient support groups from 15 countries: Belgium, Croatia, Cyprus, Denmark, Germany, France, Hungary, Ireland, Italy, the Netherlands, Portugal, Russia, Spain, Switzerland, and the United Kingdom.

WHAT IS OUR MISSION?

Our mission is to represent the interests of those who have scleroderma.

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 OUR VISION?

The FESCA vision is one of a world in which scleroderma is recognized 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 meeting January 2008 in Florence

WHAT IS SCLERODERMA?

Scleroderma is a chronic disease characterized by excessive deposits of collagen in the skin or other organs. The localized type of the disease, while disabling, tends not to be fatal. Diffuse scleroderma or systemic sclerosis, the generalized type of the disease, can be fatal as a result of heart, kidney, lung or intestinal damage.

A disease of the immune system, blood vessels, and connective tissue, scleroderma can attack many body systems or just a few. It is very hard to diagnose because each person may have a different combination of symptoms, and the disease progresses at different rates for everyone. While some symptoms are visible, like hard puffy skin on the hands, Raynaud's, and tightened joints in systemic forms, the most serious symptoms are hidden, and the person with scleroderma may look quite well to outsiders. Inside that person, the lungs, heart, kidneys, and gut are only some of the systems that may be affected. On the other hand, sometimes the face alters significantly although the organs are healthy, and facial changes may be hard to accept.

SCLERODERMA IS MORE THAN SKIN DEEP

WHAT HAPPENS IN SCLERODERMA?

The causes of the different types of scleroderma are not known, but we do know what happens: the auto-immune system malfunctions, so that the body places excess collagen on its connective tissue (which makes up the skin, joints, tendons, and parts of the internal organs). Damage to the blood vessels, meanwhile, causes them to constrict and stiffen, and weaken the organs they supply.

WHAT CAN BE DONE?

Thankfully, there are now very successful treatments that can halt the progress of scleroderma, but each of these applies to specific symptoms. There is no overall cure. It is extremely important that diagnosis is made as early as possible, so that treatment can begin if required.

HOW CAN SCLERODERMA BE DIAGNOSED?

An informed doctor can diagnose Scleroderma through a combination of medical history, physical examination, blood tests, and non-invasive investigations such as capillaroscopy.

WHO GETS SCLERODERMA?

Scleroderma is classified as a rare disease, and we think perhaps 1 in every 10,000 people may have it. We know that women are affected four times as often as men. It is not contagious or infectious.

EULAR

The European League Against Rheumatism (EULAR) is the organization which represents the patient, health professional and scientific societies of rheumatology of all the European nations. EULAR endeavors to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic diseases. In line with UEMS, EULAR defines rheumatology as including rheumatic diseases of the connective tissue, locomotor and musculoskeletal systems (www.eular.org).

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.

(www.eustar.org)

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 VEDOSS (Very Early Diagnosis of Systemic Scleroderma), a project led by EUSTAR.

In January of alternate years, EUSTAR holds an educational course in scleroderma for between 100 and 200 rheumatologists. The FESCA general assembly is also held every year in January and synchronized with the EUSTAR meetings for mutual benefit.

EULAR CONGRESS 11TH – 14TH JUNE 2008 PARIS

Excellent News for Orphan Diseases

EULAR (European League Against Rheumatism) have developed a strategy for the next 5 years 2008 - 2012 and have 8 Objectives. Objective 1 is that by 2012, EULAR will have strengthened activities in areas that are currently less prioritized, such as non-inflammatory and orphan diseases.

Even better news for scleroderma is that EULAR have chosen scleroderma as the orphan disease to concentrate on for the next 5 years and are developing research programs.

EUSTAR Chair Describes Future Research Projects

“In the year since the renewal of the board in Barcelona, EUSTAR has launched three important projects, supported by EULAR, in order to increase awareness of scleroderma and to foster the study and early diagnosis of the disease, as well as to improve the education and the care of patients through evidence-based strategies”, reported Prof. Marco Matucci Cerinic, chairman of EUSTAR.

"The first project was to transform the original database, called Minimal Essential Data Set (MEDS), into an online database called MEDSonline," said Prof. Alan Tyndall, Secretary of EUSTAR, and Prof. Ulrich Walker, chairman of the Database Committee. MEDSonline will include prospective data-sets on all sequential patients attending scleroderma clinics in Europe and elsewhere around the globe. "Having such a readily accessible online database will allow researchers to track special subgroups of systemic sclerosis (SSc) patients for later studies," stated Prof. Tyndall.

Over the past 4 years, more than 7,000 patients have been registered with follow-ups in MEDS. This resulted in publications addressing the main results obtained by the preliminary analysis of the data (Tyndall et al Ann Rheum Dis 2005;64:1107 & Walker et al Ann Rheum Dis 2007;66:754), and showed the interesting finding of centre differences rather than geographic clinical patterns of SSc in Europe (Walker U et al, Ann Rheum Dis in press). Further analyses are in preparation, including analyses on myocardial dysfunction, pulmonary artery hypertension, erectile dysfunction, arthritis, incident digital ulcer patterns, the use of anti-TNF-alpha, and details on causes of death.

The early diagnosis of scleroderma is now a pivotal issue for EUSTAR. A project on Very Early Diagnosis of Systemic Sclerosis (VEDOSS) was launched this year during the business meeting. Initially, the project will involve the creation of scleroderma clinics devoted to the early diagnosis of the disease throughout Europe.

The Basic Science Committee has finalized guidelines on cell culture and fostered the publication of papers on shared EUSTAR projects. Moreover, "the project of biobanking, supported by EULAR, is under preparation and will be launched at next year's EULAR Congress in Copenhagen," stated Prof. Oliver Distler, chairman of the Basic Science Committee.

EUSTAR showed its commitment to education by conducting two courses, one in 2005 and another in 2007, organized by Prof. László Czirják, board member, and Prof. Ulf Müller-Ladner, treasurer of EUSTAR; each course was attended by 90 advanced trainees and 30 teachers.

The next course is taking place in January 2009 in Paris under the direction of Prof. Yannick Allanore. During the course, "the correct approach to skin scoring techniques using real patients will be presented together with real application on scleroderma patients," said Prof. Czirják and Prof. Dan Furst, organizers of the skin scoring session. In addition, the umbrella organisation of patient support groups, called the Federation of European Scleroderma Associations (FESCA), represented by Kim Fligelstone and Ann Tyrrell Kennedy, have been working as active partners in EUSTAR. "They are participants at every level, to the mutual benefit of all," says Prof. Matucci.

Thanks to a very generous grant from EULAR through ESCISIT, a task force of European, North American, and Japanese colleagues, together with patient representatives (FESCA), completed a recommendation consensus process concerning the drug treatment of SSc. The set of recommendations presented last year in Barcelona will be published in the Annals of Rheumatic Diseases before the end of the year.

FESCA (Federation of European Scleroderma Associations) and EULAR

(Article from Scleroderma News Summer2008, from the Scleroderma Society)

EULAR very kindly provided FESCA with a stand during the Congress which enabled us to meet with many interested delegates. FESCA representatives who manned the stand were kept busy with visitors during the exhibition opening hours and while we had our own meeting on Friday, volunteers from ASF the Association de sclérodermiques de France held the fort.

The date for European Scleroderma Awareness Day is 29th June with the first celebration in 2009. EUSTAR will be launching VEDOSS (Very Early Diagnosis Of Systemic Sclerosis) to coincide with this date. This project is to include the establishment, in partnership with EUSTAR, of a programme whereby primary care health professionals throughout Europe will be educated in the earliest symptoms of scleroderma and asked to send any patients presenting with two or more of these symptoms to special SSc clinics, Connective Tissue Disease clinics, or participating rheumatologists.

We were joined by Elaine Furst from the Scleroderma Foundation in the USA to brainstorm topics and programme for the first Systemic Sclerosis World Congress, February 11 - 13th 2010 in Florence, Italy. FESCA together with the Scleroderma Foundation (USA) will be organising a patient programme to run concurrently with the scientific programme. More details when they are available. We are looking for sponsorship; if you know of a Company or Institution who would be interested in supporting the Conference please contact Kim. We will require professional translators for the patient programme and hope to keep registration, meals, and accommodation costs to a minimum in order to attract as many people with systemic sclerosis as possible, but to do this, sponsorship is absolutely vital. We were also joined by Birte Gluesing, EULAR PARE secretariat to offer support in the form of expertise (which is invaluable). FESCA is already benefiting from this and adapting the EULAR Standing Committee of People with Arthritis and Rheumatism in Europe's, ethical code.

In addition to the above projects (which I suspect will keep us busy for some time) the website www.fesca-scleroderma.eu, is still being developed but please feel free to take a look.



FESCA Delegates in Paris



EULAR Congress 2009
Copenhagen Denmark
10-13 June 2009

EUROPEAN SCLERODERMA DAY

29th June 2009 will be the first EU Scleroderma Day.

The artist Paul Klee, who suffered from scleroderma, died on June 29th 1940. This is the reason why this is the date for EU SCLERODERMA DAY.

Having a disease that nobody has heard of is a lonely business. When even the doctors cannot recognize it, or tell you what is going to happen, it is lonelier still.

So Scleroderma Day was created to tell people, including the medical community, what it means to have this disabling disease. June 29 is a day to recognize the bravery of those who live with scleroderma, and to demand equal treatment and equal care for people with scleroderma across Europe.

POSTER EUROPEAN SCLERODERMA DAY



Paul Klee, Kettledrummer 1940, 270 (coloured paste on paper on cardboard), 34.6 x 21.2 cm, Zentrum Paul Klee, Bern, DACS 2008

June 29 European Scleroderma Day

Scleroderma: More Than Skin Deep

The great Swiss artist Paul Klee died in 1940 of scleroderma, which strongly influenced his creative art. Scleroderma is the name given to a group of rare conditions that can damage the skin, blood vessels, and internal organs. It has varied symptoms but early diagnosis and treatment can prevent the worst complications.

The Federation of European Scleroderma Associations (FESCA) believes that people with scleroderma should have equal access to treatments.

To find the events celebrating Scleroderma Day in your country, visit our website at www.fesca-scleroderma.eu or contact your local support group.



PAUL KLEE



Paul Klee was born December 18, 1879 in Münchenbuchsee (Switzerland), near Bern, but received his father's German nationality. Paul's father, Hans Klee, taught music at the Hofwil Teacher Seminar near Berne. In his early years, Paul wanted to be a musician, but decided on the visual arts in his teen years. He studied art in Munich with Heinrich Knirr and Franz von Stuck. After travelling to Italy and then back to Bern, he settled in Munich, where he met Wassily Kandinsky, Franz Marc and other avant-garde figures, and became associated with the Blaue Reiter. Here he met Bavarian pianist Lily Stumpf, whom he married; they had one son.

In 1914, he visited Tunisia and was impressed by the quality of the light there, writing "Color has taken possession of me; no longer do I have to chase after it, I know that it has hold of me forever ... Color and I are one. I am a painter."

Klee worked with many different types of media - oil paint, watercolor, ink and more. He often combined them into one work. He has been variously associated with expressionism, cubism and surrealism but his pictures are difficult to classify. They often have a fragile child-like quality to them, and are usually on a small scale. They frequently allude to poetry, music and dreams and sometimes include words or musical notation. The later works are distinguished by spidery hieroglyph-like symbols. His better known works include Southern (Tunisian) Gardens (1919), Ad Parnassum (1932) and Embrace (1939).

Following World War I, Klee taught at the Bauhaus, and from 1931 at the Düsseldorf Academy, before being denounced by the Nazi Party for producing "degenerate art". Composer Gunther Schuller also immortalized seven works of Klee's in his Seven Studies on Themes of Paul Klee. The studies are based on a range of works, including Alter Klang [Antique Harmonies], Abstraktes Terzett [Abstract Trio], Little Blue Devil, Twittering Machine, Arab Village, Ein unheimlicher Moment [An Eerie Moment], and Pastorale. In 1933, Paul Klee returned to Switzerland; in 1935 he was diagnosed with scleroderma. The progression of his disease can be followed through the art he created in his last years. He died in Bern in 1940.

SOME OF KLEE'S ART



Insula Dulcamara
1938 (210 Kb); Oil on newsprint, mounted on burlap,
31 1/2 x 69 in; Klee Foundation, Bern



Embrace
1939 (140 Kb); Paste color, watercolor, and oil on paper, 9 1/2 x
12 1/4 in; Collection Dr. Bernhard Sprengel, Hanover



Captive
1940 (210 Kb); Oil on burlap, 18 7/8 x 17 3/8 in; Collection Mr. and
Mrs. Frederick Zimmerman, New York

SOURCES

Artinthepicture.com: http://www.artinthepicture.com/artists/Paul_Klee/Biography/

WebMuseum: Paul Klee: <http://www.sai.msu.su/wm/paint/auth/klee/>

FESCA: International Non-Profit Association
Registration number: FOJ 15454

Links to national scleroderma support groups may be found on the
FESCA website:

www.fesca-scleroderma.eu

The FESCA website serves as a centre for information exchange.
Countries who wish to develop support organisations, and new
groups who wish to join FESCA can email

info@fesca-scleroderma.eu

Comprehensive information on our activities and on related
European actions will be provided to all members.

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