



FESCA NEWS

2ND EDITION, OCTOBER 2009

Welcome to the second edition of FESCA NEWS!

In this edition you can read about:

- [the EULAR congress that was held from 10-13 June in Copenhagen, Denmark;](#)
- [the first EU Scleroderma Day which was celebrated on 29th June;](#)
- [the first SSc World Congress 11-13 February 2010 in Florence, Italy.](#)

EULAR CONGRESS 10-13 June 2009

The Federation of European Scleroderma Associations just held a stand at the EULAR Congress in Copenhagen.

Annelise Roennow the international-FESCA contact from the Danish Association was responsible to organize the stand and the layout. The location of the stand was , stand NP 9 total 9 sq.m. (3 x 3) located in hall C5 where the following activities took place:

- Eular village including seating areas, history of the Eular society, non profit associations in the field of rheumatism and a scientific café
- Cyber café
- Annals of Rheumatology booth (Eular Journal booth)
- Allied Health Professional booth
- People with Arthritis and Rheumatism in Europe booth



Annelise placed Scleroderma Day posters on the walls of the stand, and on the table different information leaflets from FESCA and member associations and EUSTAR were available for those who needed more information about us and in relation to scleroderma. Also a big Roll-up promoting European Scleroderma Day was produced for this event.

FESCA would like to thank Annelise Roennow for her wonderful work in organizing this stand. It was very difficult for her, as Annelise lives completely the other side of Denmark, and she worked very hard. It was a super job---prima! The stand looked lovely.



FESCA also likes to thank all those on her team from Denmark's young association, for their work at the stand over the four days, and making sure it was never left unattended. We were very pleased by the constant number of visitors at an event where there was so much to do. We would like to thank Annelise and all the Danish helpers from the local Association for their help organizing and helping FESCA at EULAR.

On Thursday, 11th June from 2 pm there was an unofficial FESCA working meeting for those who represented their countries and also took turns at the stand: Ireland, the Netherlands, Spain, Denmark, Cyprus and Hungary.

Ann Tyrrell Kennedy, acting president of FESCA held two very interesting and useful lectures at EULAR Congress on 12th June, Friday where the main topic was scleroderma . This was again a good opportunity to promote FESCA and scleroderma in the Congress which was the main objective of our association.

The title of the presentations:

1. Rare but not less severe – The challenge to care for people with rare rheumatic diseases (*A. Tyrrell Kennedy, CEO and Acting President FESCA, Irish Raynauds and Scleroderma Society, Dublin, Ireland*)
2. EXPLORING THE ROLE OF PALLIATIVE CARE FOR PEOPLE WITH SYSTEMIC SCLEROSIS (*M.C. Lynch1, A. Tyrrell Kennedy2 1Development, Irish Hospice Foundation, Nassau St; 2CEO and Acting President FESCA, Irish Raynauds and Scleroderma Society, Dublin, Ireland*)

1st EU Scleroderma Day 29 June 2009

29th June 2009 we celebrated the first EU Scleroderma Day.

The artist Paul Klee, who suffered from scleroderma, died on 29th June 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. 29th June 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.

Almost every member organization promoted Scleroderma and celebrated EU Scleroderma Day. Read their stories.



Italy, The Associations AILS, ASSMaF, GILS

The Associations AILS, ASSMaF and GILS, Italian members of FESCA, have announced, in Italy, a press conference, that was held on 24th June, at Palazzo Castiglioni, Corso Venezia, in Milan.

In front of a journalist's stalls have attended the doctors: Marco Matucci Cernic, Carlo Crosti, Francesco Indiveri, Carlomaurizio Montecucco, Raffaella Scorza, Ilaria Galetti, representative of Italy in FESCA and Vito Di Tano, world champion of cyclo-cross.

"The Raynaud phenomenon and the anti-nucleos antibodies' positivity" explains M. Matucci, Chairman of EUSTAR and Professor of Rheumatology in Florence "must be sufficient to direct patients at the EUSTAR centers, where it will be determined the primary or secondary nature of the R. phenomenon and after it will be, eventually, diagnosed the Systemic Sclerosis, in order to begin, as soon as possible, an adequate treatment and also contain the development of the pathology."

The Raynaud phenomenon is a constant clinical sign, caused by the alteration of the peripheral microcirculation; it appears with a paleness of hands and feet fingers, with a decrease of skin temperature, with pain and hypersensitivity, with trophic injuries and ulcers, to reach the gangrene. This is a pathology that has serious dermatologic complications.

Carlo Crosti, Director of the Union Operation of Dermatology at the University of Milan, clarifies:

"The most evident manifestation is the variation of skin consistence, that appears smooth, lucent and has a nacreous aspect. Face is often without mimic, unable to corrugate forehead, lips become smaller and thin."

Systemic Sclerosis often involves vital organs as gastro-intestinal apparatus, lungs, kidneys and heart. The gastro-intestinal tract represents, after skin, the second most frequent target of Systemic Sclerosis and it is characterized by functional alterations and by morphological abnormalities. Heart, instead, is implicated with the involvement of pericardium.

"Recently, our group has studied these aspects of the disease" says F. Indiveri, Ordinary of Internal Medicine in Genova. "acquiring data that shows how patients, who haven't symptoms of a cardiopathy, actually, could have an altered compliance of the myocardial, visible with magnetic resonance."

Clinic research have made lot of progresses in treatments of these complications and Italian clinical researchers are at avant-garde in this area.

Ilaria Galetti represents Italy in FESCA, ill with Scleroderma since twelve years, describes the difficulties of a patient of Systemic Sclerosis in everyday life. Difficulties that could take until at disability. She underlines the importance of the recognition this pathology as a rare disease, because, in this way, there would be a greater Scientific Research and specific medicines to treat it.

She continues underlining the necessity of an early diagnosis and, she asks, together with the associations, for a tutelage of patients and a support of their families, by Institutions.

Even the intervention of Vito Di Tano, world champion of cyclo-cross, explains the experience of a Scleroderma patient: the symptoms, the problems, his reactions when he discovered to be ill with this disease and, last but not least, the strength to fight it.



Italy, A.S.S.Ma.F.

29 June 2009 – A day to remember

Today is a day which should not be forgotten because it is the first day in Europe dedicated to my illness. I have Systemic Sclerosis, and recently became the president of the A.S.S.Ma.F. Onlus (Association for the Study of Systemic Sclerosis and Fibrosing Diseases). This is my first opportunity to take to the public attention an illness that has changed my life and many others like me. The association and doctors from the “Centro di Riferimento di Firenze” dedicated to finding a better treatment for systemic sclerosis chose the most visited central piazza Repubblica in Florence to present the event.

In the booth, posters from FESCA were present and patients and volunteers distributed informational materials, collected donations and spoke with the public about the illness. In a separate tent, doctors performed videocapillaroscope for anyone who wanted to be screened.

Before the event, the association communicated the event of the European Scleroderma Day and activities via newspaper, television and radio advertisements. On 29th June, journalists from several newspapers came to interview us and the medical staff directed by Professor Matucci (President of EUSTAR) who explained the scientific characteristic features of the disease. Me, as president of the association, spoke about the discomforts of living with the disease. Together we also called attention to the fact that we chose to educate the public about this rare and widely unknown disease on 29th June because it is also the date of the death of the great artist Paul Klee who died of Systemic Sclerosis.

Our effort was well received and many people came to the event after the advertisement showing the importance of an early diagnosis to prevent disease evolution.

In the next year, I would like that this year to have many days like this, where Systemic Sclerosis is discussed.

This is a day which we will not forget, and I hope, will only be the first of many others, in which this unknown disease is the center of attention for European doctors.

Our association hopes to assist the patients, promote scientific research and spread knowledge about Systemic Sclerosis. We hope that our association, together with the other FESCA associations, have had a POSITIVE impact on the public raising the awareness of the disease.

Camilla Sandrucci





Hungary, Scleroderma Association

Celebrating the 1st European Scleroderma Day by organizing the 1st National Conference for People with Scleroderma.

The Hungarian Scleroderma Association as member of FESCA has joined to organize the first European Scleroderma Day. Being a relatively young organization, founded 4 years ago in 2005, our main aim on this special day for people with scleroderma was to increase awareness of the disease among patients as the primary target group all over the country, treated in different medical centers, secondly among doctors handling patients with scleroderma as secondary target and last but not least for the Ministry of Health.

We started with a small PR article about the Conference and Paul Klee in the first best sold women's magazine, Kiskegyed. Also posters and leaflets were placed in the main clinics (Pécs, Debrecen, Budapest, Szeged) contacting the head of departments personally introducing Scleroderma Day and asking for support. The main event of this day was the 1st National Conference for People with Scleroderma organized purely by our association in



Budapest on the 29th of June 2009 at European Scleroderma Day combining with a press conference. We proudly can say that the interest was so high among patients not only in our association but among those who never heard of us that more than 160 people participated in the Conference where we planned only for 100. People came from all the main University Clinics-Centers of Hungary. The main topic of the Conference was 'How to live with scleroderma?' Beáta Garay Tóth, president of the Association, opened the conference. The main Patron of the Conference was Prof. Dr. László Czirják, Director of the Pécs University Clinic Center Immunology and Rheumatology Clinic, who was one of the honored lecturers of the day. He talked about scleroderma, its cause, what it is, whom can be affected and other important symptoms, an overall view on the disease. Also he emphasized the importance of and talked about VEDOSS Project, work of EUSTAR and EULAR how they help the recognition and treatment of scleroderma. Dr. Gabriella Szűcs from Debrecen University Medical Centrum Rheumatology Department continued with her very complex and detailed lecture by presenting the treatment options in systemic sclerosis based on the Recommendation developed by EUSTAR and other new opportunities which are not yet so common and not certified totally yet. Dr. Marianna Nemeskéri from the head of the Health-politics Department of the Ministry of Health held a speech about the care and provisions of people with scleroderma in Hungary. While the audience had a lunch break, Prof. Czirják, Dr. Szűcs and President Garay-Tóth went directly to the press conference where more than 15 media were present. There all three lecturers give a speech to the media people and then answered the questions for one and a half hour long. After this event and the lunch the Conference continued with the exciting and interesting lecture of Dr. Cecília Varjú from Pécs University Clinic Center Immunology and Rheumatology Clinic about the rehabilitation. She also gave and called the attention to practical advices how to live with scleroderma (exercises, breathing, eating, GI function, sexual life, importance of warm, handling cold hands, etc.). Béla Szabó, vice-president of the Association talked about his experiences and why his philosophy is "he is not ill, only he has scleroderma", how he stayed in work and how family can help him and why it is not good if people talks to each other about treatments and symptoms in the hospital which is a scare for all of us. Finally Beáta Garay-Tóth, president, had a speech about the Association, its aims, activities, future plans and about FESCA and the importance of Scleroderma Day. This conference and Scleroderma Day was a very important milestone in the life of our association and also in the acknowledgment of the disease itself. Also doctors from the main medical centers and decision makers from the governmental area were present to see the importance of scleroderma and why it is so crucial to continue dealing with it for the very early diagnosis. More than 20 articles appeared in different type of journals: women's magazine, dailies, e-news, radio and regional papers. More than 30 people joined to our associations and regional club meetings will be developed in the main medical centers.



United Kingdom, The Scleroderma Society

The Scleroderma Society published an advert in the British Medical Journal (GP version) to publicize Scleroderma Awareness Day, and to highlight the importance of early diagnosis among GPs. We also sent the FESCA poster and leaflets to every rheumatology department in every hospital across the UK, asking them to pin up the poster and put out the leaflets. We also had an information stand and banners promoting scleroderma awareness day on 29 June in the Royal Free Hospital in London, and handed out many leaflets about scleroderma, as well as talking to the many visitors we had and telling them about scleroderma. These people were many hospital staff, and visitors to the hospital. We also asked all our members to pin up the FESCA poster somewhere where lots of people would see it, such as in a doctor's surgery, library or shop. Hopefully there were posters advertising scleroderma day pinned up in different places across the UK!



United Kingdom, Raynaud's and Scleroderma Association

The Raynaud's & Scleroderma Association had a slot on both Health Matters and Talk Radio Europe today. Anne Mawdsley gave in depth interviews about scleroderma, the importance of Scleroderma Day and the work of FESCA. This has certainly helped to increase awareness.



Denmark, Scleroderma and Raynaud's Society

In Denmark they have translated the Scleroderma Poster into Danish and distributed it to many libraries all over the country. They also sent it to many hospitals. Next year they hope for more activities.



Ireland, Scleroderma Society

EU Scleroderma Day celebrated in Ireland

In Ireland on 29th June 2009 the inaugural Scleroderma Day was celebrated at a launch-event in Trinity College, Dublin, attended by the Minister for Health, Mary Harney, and other key political figures. Doctors, patients, science and industry leaders, and media were addressed by the Minister and consultants, who spoke about the need for early diagnosis of this disabling disease.

In the lead-up to the day, press releases had been distributed to the media, radio and print interviews were conducted, and an information campaign using leaflets and posters had taken place throughout the country.

Every General Practitioner (GP) in Ireland, every rheumatologist and every dermatologist, and many other medical practitioners as well, were sent a letter by the FESCA member organization, the Irish Raynaud's & Scleroderma Society, inviting all GPs to the event and enclosing a package of information about the diagnosis and treatment of scleroderma. Specifically, this packet included instructions for the general practice doctor to follow on finding two or more symptoms in a patient. This directive letter was signed by leading rheumatologist Professor Douglas Veale of St. Vincent's Hospital, Dublin.

This was all part of a new program launched on 29th June to speed up diagnosis of the rare condition scleroderma, also known as Systemic Sclerosis. Called VEDOSS (Very Early Diagnosis of Systemic Sclerosis), this program is an EU-wide directive led by EUSTAR and supported by FESCA. In Ireland it has the support of Minister Mary Harney and Dr. Ronan Kavanagh, President of the Irish Society of Rheumatologists.

At least 2% of Raynaud's patients develop scleroderma, a systemic connective tissue disease with high morbidity and mortality. Several different types exist, symptoms vary widely, and progression is unpredictable, making diagnosis very difficult. EULAR in June 2008 officially decreed it a rare disease in need of special focus.

Under the VEDOSS program, GPs are asked to refer to a rheumatologist or to a National Scleroderma Centre any patient with two or more early symptoms of SSc for further testing. These symptoms were decided by a team of international rheumatologists using the Delphi process, and include in order of importance:

- Raynaud's Phenomenon
- Puffy Fingers
- Antibodies (ANA, ACA, Topo I)
- Diagnostic nailfold capillaroscopy
- Calcinosis
- Digital ulcers
- Dysfunction of the esophageal sphincter
- Telangectasia

Professor Douglas Veale and Dr. Sean Gaine, Consultant in Respiratory Medicine, spoke at the 29th June launch event about the necessity to see people with two of these symptoms as soon as possible, so that treatment can begin as necessary, and PAH can be ruled out by tests. The Minister for Health gave her support for the program and for the ongoing work of the Irish Raynaud's & Scleroderma Society.

The campaign leading up to the launch of the inaugural Scleroderma Day was successful, and media coverage after the event was also extensive, with photos published in several newspapers. The IRSS now hopes to collect data on how successful VEDOSS is in increasing early diagnosis.





Spain, Scleroderma Association

In Madrid at the Spain Square a minibus drove around to advertise the Spanish SSc Day in mobile fashion. There were placed information points in the most important hospitals in Madrid and also in some important hospitals in Seville and Navarra. In the afternoon the minibus visited the hospitals in Madrid where the information points were situated. Throughout the day

interviews were given to several reporters of radio stations and journalists of newspapers to promote Scleroderma. A website opened for marketing promotion for SSc Day and all events.



Portugal, the Portuguese League Against Rheumatic Diseases

The Portuguese association held a conference to celebrate SSc Day. Rheumatologists, psychiatrists, GPs, social welfare stakeholders, patients and families, and also the general public were invited to launch SSc Day.



Cyprus, Cyprus League Against Rheumatism

Cyprus League Against Rheumatism organized for the 1st time Scientific meeting for Doctors of different specialties (Rheumatologists, Pneumonologists, Nephrologists, Vascular surgeons, dermatologists) for Scleroderma on the 27th of June 2009. The scientific meeting was supported by the Cyprus Rheumatology Society and the participation of doctors from Cyprus and Greece. The key speaker on Scleroderma was Dr. Vlahogiannopoulos from Greece along with seven other rheumatologists and pneumonologists. The scientific meeting was under the auspices of the Minister of Health Dr. Christos Patsalides and the support of the Cyprus Medical Association. Our League invited 1300 doctors of different specialties to take part in the scientific meeting however 50 persons participated due to different milestones.

All 1300 doctors received also an information leaflet about Scleroderma that was produced by FESCA and translated in Greek. This leaflet was also given to members of our League for information. The poster made by FESCA was translated also in Greek and was modified in order to promote the scientific meeting and was put into hospitals and clinics all over Cyprus aiming to inform people about Scleroderma and doctors about the meeting.

The scientific meeting was filmed by a professional filmmaker and DVD including the lectures and presentations of that day and copies of the DVD was sent to the Minister of Health as well as all the speakers.

As part of the campaign for informing the general public about Scleroderma members of our League were invited to talk to a number of radio and TV programs and shows and also different articles were written in a number of Cypriot newspapers.



The Netherlands, NVLE Patient Organization for Lupus, Scleroderma and MCTD

In connection with the EU Scleroderma Day on 29th June 2009 the NVLE organized a scleroderma patient congress on 27th June 2009 in collaboration with the Sint Maartenskliniek in Nijmegen and dr. Van den Hoogen. The theme was a Dutch saying (something like): 'Scleroderma smashing art'.

The day was filled as followed:



In the entrance hall an exhibition from a professional photographer with pictures from typically scleroderma appearances was presented and scleroderma patients showed their own made art on stands.

In the introduction dr. Van den Hoogen spoke of Paul Klee and he explained why 29th June has become the date for the European Scleroderma Day. Some of Klee's art was shown.

Then young physicians spoke about the developments with relation to medication and treatments in plain speech.

Wendy Vergouwen, member of FESCA, told something about the come into existence and the vision and mission of FESCA.

For the rest a patient read pieces from her journal and in between there was entertainment.

The poster was sent to the big hospitals and the leaflet (translated into Dutch) was handed out to the visitors.



Germany, Patient Organization for Scleroderma

On SSC Day the Sklerodermie Selbsthilfe e.V. organization in Germany arranged a press conference with well-known doctors, afflicted patients and journalists/ reporters in the surrounding of the Frankfurter Pressclub.

The press conference took place in Frankfurt. They wanted to use the publicity to make the rare disease scleroderma public. They also talked about their work and the work of FESCA, which is very significant and important for all the European countries, but also for the whole globe. In this connection they remembered the day of death of Paul Klee.



Belgium, Patients Association for Scleroderma (APSB), League for Chronic Inflammatory Connective Tissue Diseases (CIBLIGA)

Belgium and its First Scleroderma Day

Both patient groups of Belgium (Dutch and French speaking) worked together to organize a bilingual press conference in Brussels.

A few days later, an information stand was held in the railway station of Antwerp, one of Belgium's most important stations.

The press conference was the first experience of that kind. Great excitement to all of us ... will the journalists come along ? Would we be convincing enough to obtain the journalists' attention to make them write and talk about Scleroderma ?

Files in both languages were distributed and professors of University Hospitals gave medical information. Last but not least, patients gave their testimony of the illness.

Although only a few journalists came, a lot of articles were written in the national as well as in the regional papers.

Interviews could also be heard on the radio in French and Dutch.

One of those interviews made it possible to talk more extensively about the information stand that would be installed a few days later, on the very 29th June, in the Antwerp Railway Station.

This appeared to be very useful. We indeed noticed that several unknown patients came to the station to get information, as they had heard about the stand on the radio. About 10 patients became members of the association, and were very glad to have the opportunity to talk to another suffering the same way.

Folders about scleroderma, with in front page a picture of a painting of Paul Klee were handed to hundreds of hands. We were happy to see that some of the travelers knew about our action due to the press' attention.



Thanks to the good care of all volunteers, the first Scleroderma Day will probably remain a good memory for everybody.



Yes, we reached our achievement : on 29th June 2009 Belgians talked about scleroderma! And this, of course, gives one the necessary energy to work something out next year.



France, Scleroderma Patient Organization

The French Association celebrated 20 years of Existence this year. A whole week of celebrations and 8th and 9th of May were dedicated to scleroderma. A video-clip of 30 seconds was transmitted on TV throughout that week, and was repeated also on the 29th of June. It was transmitted to 5 different channels. Also on 29th June a press conference with doctors was held, together with a press release, and the same article was sent to all French media.

1ST SYSTEMIC SCLEROSIS WORLD CONGRESS

In February 2010, a World Scleroderma Congress will be held in Florence. This will be a dual event, consisting of a 3-day congress for doctors, and a one-day event for patients at which rheumatologists will address issues of interest to people who have scleroderma. All lectures and events will be in English, but FESCA is investigating the possibility of translation.

The congress will be a worthwhile trip for couples, families, or groups of friends. Not only will the speakers be world-class, but Florence is a wonderful destination that is fun to visit –and magical for Valentine’s Day weekend.

The patient congress will be held on Friday 12th February from 10 am until 2 pm. Before and after, visitors will be able to sightsee, enjoy the city’s views and restaurants, and go to the museums and churches. A tour of the city will be arranged for those who want.

Those who register for the congress will have to pay only € 25.00 as a subsidized attendance fee, and hotel accommodation can be booked at preferential rates. Flights can be booked into Florence airport, and cheap flights are available on RyanAir into Pisa, from where there is a direct bus to Florence. Accommodation is booked through the local travel agency AIM.

The occasion is being planned as a networking event for Scleroderma patients as much as an information-gathering event. We do not anticipate large numbers, and the congress will not be stressful or over-long. Please contact your national organization to learn more.

Dates of medical congress: 11 February - 13 February, 2010

Date of patient congress: Friday 12 February, 2010

Location: Florence, Italy

Patient Program

Friday 12 February

Patients are, in addition, most welcome to attend any of the scientific sessions held in the Medical Program, which extends from Thursday 11 February at 14.00 until Saturday 13 February at 17.45.

Patients select which morning sessions they wish to attend, as part of registration. Patient Sessions in Rooms A and B are in English with simultaneous translation into Italian.

Each session is 45 minutes followed by 15 minutes questions.

Each room holds approximately 50 people

Room A

10-11 am	Dr. Fred Wigley	Raynaud's Disease
11-12 noon	Dr. J. Van Laar	Treatments for SSc
12-1 pm	Dr. J. Seibold	Cardiovascular issues in SSc

Room B

10-11 am	Dr Chris Denton	Renal complications in SSc
11-12 noon	Dr. Yannick Allanore	Musculoskeletal issues in SSc
12-1 pm	Dr. R. Silver	The Lungs in SSc
1-2 pm:	LUNCH	

Room A-- JOINT SESSIONS

2-3 pm	Dr. L. Czirjak	Gastro-Intestinal tract in SSc
3-4 pm	Ms. Elaine Furst, R.N., M.A. Beata Garay-Toth, FESCA V-Ptd>	Living with Systemic Sclerosis
4.00-4.30 pm	Dr. Wigley Dr. Denton Dr. Van Laar	Discussion Panel/Patients questions

REGISTRATION

Contact: Chantal Lemieux

Phone: 39-0-552-881 **Fax:** 39-0-552-480-246 or **email:** sclerosis2010@aimgroup.it

BOOKING FOR ACCOMODATIONS

It can be done through the agency AIM whose link is to be found on the World Congress website.

The links are:

- <http://www.medical.theconferencewebsite.com/conference-info/1-Systemic-Sclerosis-World-Congress-2010>
- <http://www.aim-internationalgroup.com/2010/sclerosiscongress/>



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 organizations, 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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