



FESCATM

Federation of European Scleroderma Associations

FESCA NEWS

News from the Federation of European Scleroderma Associations, Winter 2013



Welcome from our President

Dear friends,

This year has seen FESCA grow in strength as it becomes more widely recognised as the united voice of European people with scleroderma. Each individual national society responds to the needs of people in that country, providing support and advocacy. But to develop advocacy on the EU level, support on the global level, and awareness of scleroderma on the world stage, we need an umbrella organisation to provide numbers that will attract notice and act as a point of reference for law-makers, industry, and research.

This year saw the initiation of the major research project DeSSciper, of which FESCA aisbl is an integral partner. All scleroderma research projects in the EU now call upon us to get the information to our members so that sufficient patients can be enrolled. There are no new treatments without research. There is no research without patient participation. And this year has seen that rare and wonderful thing: new treatments for SSc. It is a far more hopeful world than it has ever been.

At our AGM in Porto this year, we met new members and new representatives. Change is always revitalising, and we constantly welcome new ideas and new energies. Above all, we need now to find a way to raise funds to support medical research. Unity is our strength. If researchers now run EU-wide projects, we, the patients who benefit from these, can surely find EU-wide ways to support them.

As always, our major awareness campaign of the year was World Scleroderma Day, and this issue is dedicated to some of our countries and their fantastic campaigns. What a successful idea this has proved to be!

Coming up is our most important challenge: the World Scleroderma Congress in Rome, February 6-8, immediately followed by our AGM 2014. We are really proud of our programme for the patient congress, which has such a varied offering of



sessions that I know there will be something to meet every need and to answer every question. Fatigue, pregnancy, sexuality, men with SSc, children, breathing exercises, make-up workshops—even a session where you can ask any question of two senior professors. In the pages of this newsletter you will find information about the programme and how to register.

I look forward very much to seeing you in Rome with a contingent from your country. In the meantime, let's all keep warm as the cold weather approaches. Fingers crossed for a mild winter!

Alex Kennedy

Editor's note



This edition we are celebrating and focusing on the wonderful activities of World Scleroderma day, 29th June.

We would like to publish articles on events taking place in our member organisations' countries across Europe so send us your news! Please send your contributions for future newsletters to susie@sclerodermasociety.co.uk. Do wrap up warm for winter and I look forward to meeting as many people as possible in Rome in February for the World Congress!

Susie, Ed

Approval has been awarded for a new, oral drug to treat pulmonary arterial hypertension (PAH) by the US Food and Drug Administration (FDA).

The approval of Macitentan, also known as Opsumit[®], for the treatment of pulmonary arterial hypertension, is excellent news for patients who suffer from this severe symptom of scleroderma. The US FDA is known for its rigorous regulations.

Actelion announced on 18 October that the FDA has approved the use of the orally available endothelin receptor antagonist Opsumit[®] (macitentan) 10 mg once daily, for the treatment of PAH to delay disease progression. The new drug has significantly fewer side-effects than prior drugs including Bosentan[®].

Effectiveness was established in a long-term study in PAH patients with predominantly WHO Functional Class II-III symptoms treated for an average of 2 years. Patients were treated with Opsumit[®] monotherapy or in combination with phosphodiesterase-5 inhibitors or inhaled prostanoids. Patients had idiopathic and heritable PAH (57%), PAH caused by connective tissue disorders (31%), and PAH caused by congenital heart disease with repaired shunts (8%).

Dr. Vallerie McLaughlin, Director of the Pulmonary Hypertension Program in the Division of Cardiovascular Medicine at the University of Michigan, commented: "Over the past twenty years, great strides have been made in treating PAH patients. However, there has been a medical need for innovative treatments that improve long-term outcomes. Opsumit[®] is the first clinically proven and only oral treatment option indicated to delay disease progression and reduce the need for PAH hospitalization."

Dr. McLaughlin concluded: "These effects were demonstrated in SERAPHIN, the first and largest PAH outcome study to date, where Opsumit[®] was given on average for 2 years, as a monotherapy or in combination with phosphodiesterase-5 inhibitors or inhaled prostanoids. I am very pleased that PAH patients will have this new treatment option."

Regulatory reviews are ongoing in Europe, Canada, Switzerland, Australia, Taiwan, Korea and Mexico.

For more information, visit this link:

<http://www.actelion.com/en/scientists/development-pipeline/phase-3/macitentan.page?>



World Scleroderma Day

Cyprus



Scleroderma Day 2013 In Cyprus focused on two areas:

- awareness among the general public, health stakeholders, and patients about scleroderma
- the launch of the DeSSciper project and the socialization of people with scleroderma.

Firstly we spread awareness by giving a press conference to the media. A doctor gave a speech about scleroderma to inform the media about the disease and its complications. He also explained and presented the DeSSciper project.

From the patient's point of view, I spoke about the problems we face in everyday life; I emphasised the need to establish a rheumatology ward in our general hospital in which patients with scleroderma should be treated.

We also sent press releases to newspapers and we gave radio interviews. Then we invited people with scleroderma, along with a companion, to attend a dinner especially arranged for them. We also invited a rheumatologist to say a few words.

Again, it was difficult to encourage many people to show up but those who came said that they want to come every year as they felt nice and comfortable among people with the same difficulties.

*Despo Charalambous,
General Treasurer of CYPLAR*



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.

World Scleroderma Day

Norway

In Norway there are less than 500 people suffering from scleroderma.



They live spread all over our long country. It is quite expensive and often rather cumbersome to travel in Norway.

If we were to arrange lectures or stands or things like that, we would reach only a few people. We therefore found it better to mark World Scleroderma Day rather than celebrate it.

We did so by putting an advertisement into a nationwide paper informing about the symptoms of scleroderma and why it is important to get in contact with experts on the disease.

We did the same in 2012, and we know the advertisement then was read by people with symptoms but no diagnosis and therefore a success!

*Liv Kristiansen
Norwegian Scleroderma Group*

Translation of advert as published on 29 June 2013 in Aftenposten, Norway, page 56.:

Scleroderma

Did you know that there is a rheumatic diagnosis called scleroderma? We are about 350 people in Norway with that diagnosis. Many of us get white and unusually cold fingers. That is called Raynaud's Phenomenon. Scleroderma attacks the skin, the connective tissue in joints, muscles, and inner organs. That is why it is important to obtain more information and receive medical treatment.

June 29th is our international day. Ref. www.fesca.eu which informs about our European contacts.

Do you want to know more? Have a look at this [link](#). There you will find useful information about scleroderma and how to get in touch with the Norwegian Scleroderma Group.

Solldagskafe på Sæterhytten kl. 12-16
www.bygdokongesgard.no
Søndag, kl. 13:00: Musikk i Paviljongen
Bygdøyveien 30

SKLERODERMI
Visste du at en gruppe personer i Norge har en revmatisk sykdom som heter Sklerodermi, også kalt Systemisk sklerose? Vi er ca. 350 mennesker i Norge med diagnosen. Mange av oss får hvite og uvanlig kalde fingre. Det kalles Raynauds fenomen. Sklerodermi angriper hud, bindevevet i ledd, muskler og indre organer. Derfor er det viktig å få mer informasjon og komme til behandling. 29. juni er vår internasjonale dag. Se www.fesca-scleroderma.eu som forteller om våre europeiske kontakter. Vil du vite mer? Se www.sclerodermi.no. Du vil finne nyttig informasjon om Sklerodermi og kontaktadresser for ditt fylke og til landsstyret.

FESTIVALKAOS Trøbbel for svensk festival
Torsdag gikk startskuddet for den nye, svenske storfestivalen Bråvalla, og det meldes om varemangel og lange køer. - De har litt å jobbe med til neste år, sier festivalbesøker Madeleine Svensson til TT Spektra.
I løpet av helgen ventes rundt 50 000 besøkere til den gamle Byplassen utenfor Norrkøping for å se artister som Rammstein, Green Day og Avicci. (NTB)



Организация на пациентите с
ревматологични заболявания в България
(ОПРЗБ)

Bulgaria

Belated report from 2012! The Bulgarian organization for people with rheumatic diseases carried out various activities on 29th June 2012 and here are some of the wonderful photos to remind us of the day!

Boryana Boteva

Bulgarian Organization for Patients with Rheumatic Diseases



Italy

AILS and GILS together organized a press conference at the Regione Lombardia to celebrate World Scleroderma Day.

We met the Vice President and Commissioner for Health in Lombardy and we spoke to him about scleroderma with our rheumatologists. Press releases have been published in many newspapers.

Ines Benedetti
Presidente AILS



Hungary



Országos Scleroderma
Közhasznú Egyesület

This year we organised a big national conference (as every 2nd year) and this time it was in a new place, in another important medical university town, SZEGED (200km from Budapest).

We had almost 100 participants from all over the country. The Minister of State for Health, Miklós Szócska, Dr., was invited to the event, but did not come. He sent a letter which was read out and the main message was that they will take care of this rare disease and will provide patients with adequate care.

The interesting thing, as a starter, was that we were also greeted by the medical students' international organisation which supports rare diseases all over the world. A very nice short video film was made by this international group of students all over the world, speaking in English, "We support you scleroderma or autism or etc." It was a very kind opening to the conference.

The main topics of the conference were:

- SSC beyond medicine;
- Psychology of chronic disease and SSC - very, very interesting and good approach from a professional psychologist;
- Me and SSC from a patient perspective - great speech from a man who is a school director, father and husband, 45 years old;
- SSC and GI tract: too serious, a true but concerning lecture about what happens in the whole GI tract and how to handle it;
- Local EURORDIS (Riosz) lecture;
- Setting up the national patient forum and its burdens, opportunities by a governmental officer from the Ministry of Human Resource, Health Department;
- DeSScipher;
- Q & A.

The press was invited to the event and we already had several press releases online, as well and myself giving a radio interview. Here is an online article about the event and DeSScipher - which is of course in Hungarian. <http://www.euroastra.info/node/72357>

*Beata Gary Toth
Hungarian Scleroderma Association*



Denmark

Dansk
Sklerodermi
& Raynaud
Forening



A small conference was arranged in Copenhagen this year with lectures from three different doctors/specialists.

The topics were:

1. Treatment of digital ulcers in hyperbaric oxygen therapy. We have three hospitals in Denmark where this treatment can be done and treatment of digital ulcers has a very good outcome;
2. Dental problems in scleroderma;
3. Raynaud's phenomenon - what is it, how do you prevent Raynaud's attacks and what treatments are available in Denmark at the moment.

Also, I introduced the projects DeSScipher and pregnancy in systemic sclerosis, and I mentioned the World Congress in Rome in February 2014.

On the side, you could buy silver gloves, and there was also a company introducing battery electric heated softshell jackets. Their website is www.nordicheat.dk.

It was a very good afternoon which started with a delicious buffet with a lot of food. Around 70 people, patients, doctors, nurses, family members came to help making World Scleroderma Day in Denmark a good day.

Annelise Rønnow
Danish Scleroderma and Raynaud's Association



World Scleroderma Day

Switzerland



We held our congress and our AGM on June 29th.

This year, we wanted to bring support to our members. The topics were :

- hypnosis and self-hypnosis;
- pain in scleroderma.

Then, we invited two people who spoke about their disease: five years ago and one year ago respectively, they had a lung transplantation. It was a intense moment of emotion and a wonderful lesson about life.

This day was held in French and in German (simultaneous translation) and we invited the lupus association and sarcoidosis association.



*Nadine Paciotti
Swiss Association of Scleroderma Patients*

Finland

In Finland, we wrote some articles; there was article on scleroderma and what it is and there was article on rehabilitation. We have a rehabilitation center in Finland called Apila. Mikko, who works there, wrote about the centre in Apila, and how to get a place in the rehabilitation centre.

A lady who works in the arthritis association wrote about the health care act. In addition, there was a press release about DeSScipher, along with some instructions on how to exercise hands.

We sent all this by mail, instead of by email only, which is what we usually do.

*Marjo Mäkelä
Finnish Scleroderma Association*



The Netherlands



On 22 June World Scleroderma Day was given much attention during the patient congress where the theme was light-hearted with the subtitle "Air - a daily necessity".

Several specialists gave presentations on the following topics;

1. New classification in scleroderma
2. Latest developments in the scientific field of scleroderma
3. Lung complications in scleroderma
4. Useful tips on being active with scleroderma
5. How do I create and maintain a social network?

Thereafter, the 230 enthusiastic participants attended the workshop of their choice with these topics;

1. Pulmonary Arterial Hypertension;
2. Physical therapy and moving;
3. A patient's perspective of living with scleroderma

During this patient congress, Linda Kwakkenbos received the NVLE award 2013 in recognition of her work in the field of psychological research in scleroderma.

*Linda and Joep
Patient organization for lupus, scleroderma and MCTD (Netherlands)*



World Scleroderma Day

Germany



On the occasion of the 50th anniversary of the rheumatology department at the Kerckhoff-clinic in Bad Nauheim we were invited by Professor Dr. Ulf Müller-Ladner – head of the department – to celebrate the Scleroderma Day with him together in his clinic.

It was a very nice atmosphere with a lot of well-known doctors and many, many patients. Because of the fact that the Rheumatology Center of Bad Nauheim is one of the largest and well-known in this area and many people are patients of Professor Müller-Ladner, for us it was one of the best chances to inform all the visitors about scleroderma and the scleroderma organisations in Germany and Europe.

In his welcome speech, Professor Müller-Ladner mentioned explicitly World Scleroderma Day and in the afternoon the deputy director of the rheumatology department informed the visitors in detail about scleroderma. It was an excellent opportunity for promotion.

Additionally the clinic staff demonstrated some tests with different capillary equipment, so the patients and all visitors could see what is the affect and results of scleroderma on capillaries. By using different tools the



results were of special interest for the doctors and specialists. First we were shown a simple optical microscope for less than 100 Euros, which is sufficient for the capillary-diagnosis, then a piece of equipment costing several thousand Euros (Ferrari) which is good enough for research and trials.

At the scleroderma stand we welcomed many visitors with a lot of questions and we informed them to the best of our knowledge. At the end of the day Professor Müller-Ladner and his assistant, Dr. Frerix, also made a visit to our stand.

At the end of this short report we congratulate and wish a happy birthday to the rheumatology department of the Kerckhoff-clinic and all the best for the future and further good collaboration between us. And many thanks also for the opportunity to celebrate World Scleroderma Day in such a nice environment.

Emma Margarete Reil
President of Sklerodermie Selbsthilfe e.V.
Deutschland / Germany





Working in Partnership



United Kingdom

World Scleroderma Day was featured in the RSA's Hot News newsletter, on the Facebook page and Tweeted by the RSA and the Scleroderma Society.

The RSA and the Scleroderma Society also produced joint-branded SoRare post-cards for distribution, with the logos and contact details of both organisations together on the cards.

The Scleroderma Society got its gloves on to support World Scleroderma Day in 2013 with a weekend full of awareness raising and campaigning. On the 28th the Society held it's now annual Get Your Gloves On! Campaign. To support awareness of scleroderma, the organisation distributed over 1,000 Get Your Gloves On! Kits. These were sent to all our members and supporters, promoted via our website and social media. The kits consisted of posters (A3 and A4), an activity pack, leaflets, stickers and a specially designed collection box. The resource pack was also sent to every rheumatology unit in the UK and promoted through organisations such as the Chartered Institute of Physiotherapists.

On the 29th, we held our annual members' conference and AGM as part of our WSD celebration. We had a number of speakers including Professor Chris Denton from the Royal Free Hospital and Dr Linda Kwakkenbos who came over from Canada to tell us about the SPIN project which is aiming to create psychological interventions for people with scleroderma.

Get Your Gloves On! went international in 2013 and the campaign was used in a number of countries to celebrate World Scleroderma Day. The campaign was used by organisations in Greece, Canada, Croatia and Australia.

Liz, Raynaud's & Scleroderma Association

Susie, Scleroderma Society

Get Your Gloves On!
for people with Scleroderma
on the 28th June 2013

You can help the Scleroderma Society carry on providing information and support for people with scleroderma. Just by wearing your gloves on 28 June!

You probably know that people with scleroderma often have extreme circulation problems and need to wear gloves or a coat, even in summer.

So we are asking people to get their gloves on to show their support, raise some money and have some fun!

If you would like more information and ideas on how to take part please telephone or email us. We can also help you organise your event and get publicity.

Scleroderma Society

020 7000 1925
info@sclerodermasociety.org.uk
www.sclerodermasociety.org.uk

World Scleroderma Day

France



In France, eight meetings were held in Paris, Lille, Bordeaux, Nice, Dijon, Hyères, Sablé/Sarthe et Carhaix-Plouguer (Bretagne), between doctors and patients.

A friendly lunch was offered for the patients. There was two new workshops in Bordeaux and Nice:

1. make-up (advice on make-up, and advice on cosmetics);
2. workshop with a dermatologist and workshop on make-up for patients' skin.

Another new idea was to organize a “speed meeting” between patients and doctors. Only doctors moved around every half an hour. They could answer the questions and exchange freely. This new option was a great success.

Information was also published in local newspapers for the patients not able to take part at these meetings.

Dominique Godard
Association des Sclérodermiques de France



This year we celebrated World Scleroderma Day with a prestige event called **"Tea For Two"**

This was held in The Dawson Restaurant, Dawson Street, a well-known venue in the heart of Dublin city. It was themed on the Mad Hatter's Tea Party from the well-known story *Alice in Wonderland* and some guests arrived dressed as characters from the story, for example the Red Queen, the Mad Hatter and Alice. The surroundings were elegant with wonderful plasterwork on the ceiling, chandeliers and marble statues.

Beautifully set tables were very inviting and a string quartet entertained the guests who were greeted with a glass of Prosecco on arrival. A delicious afternoon tea was served which included tiny sandwiches, pastries, cakes and other delights and each guest received a cup cake decorated with our logo. Information leaflets about scleroderma and about the Irish support group, now called Raynaud's & Scleroderma Ireland (RSI), were handed out.

The Executive Director, Michelle McGill, spoke about scleroderma and about the work of RSI, and she played a 5 minute section of a recently aired 45 minute radio documentary about scleroderma in which the journalist, Monica Heck, interviewed a number of our members. This was a very moving and very informative production and many guests commented later that they had learned a lot from hearing people speak about living with scleroderma.

Monica Heck's documentary led to a number of publications in the Irish press to coincide with World Scleroderma Day, including one in TheJournal.ie which can be read at the following link: <http://www.thejournal.ie/scleroderma-day-sufferers-documentary-monica-heck-971906-Jun2013/> and one in Woman's Way magazine, issued June 24th and called *The Marble Lady*, which you can read here <http://heckthehack.files.wordpress.com/2013/07/womans-way-june-24-monica-heck-scleroderma.pdf>

The *Tea for Two* event, which also celebrated the 25th Anniversary of RSI, was advertised on radio, and in the local newspapers as well as in the national newspapers. This generated significant interest and resulted in one of our members being interviewed on a national morning TV programme and on a national radio station.

A photographer was present at the event and photos of attending celebrities appeared in newspapers and social magazines, including VIP. This helped to raise the profile of scleroderma among the Irish public and made more people aware of the presence of RSI. The result has been an increase in the number of people finding us on Facebook and Twitter and we have had an increase in the number of calls from people looking for information and support.

World Scleroderma Day 2013 has been a great success here in Ireland and we would like to acknowledge, with thanks, the financial support given by FESCA, making it possible to reach more people and raise awareness.

Mary McDaid
Raynaud's & Scleroderma Ireland



World Scleroderma Day



Croatia



This year HUOS made extensive preparations to mark World Scleroderma Day. It was an excellent opportunity to raise awareness about this rare disease.

Our activities were directed towards the public and towards medical staff / physicians. At the heart of Croatia's capital Zagreb, scleroderma patients and supporters of the association along with some public figures took part in an excellent UK Scleroderma Society initiative "Get Your Gloves On!" Posters, leaflets and internet media were used to invite people to wear gloves in their daily activities to support scleroderma patients. In order for action to be most successful, association members gave out gloves with the HUOS logo and flyer which explains why the gloves are associated with scleroderma. We achieved particular success among health care personnel who have embraced participation in this action. Doctors in four regional hospitals that treat patients suffering from scleroderma (Zagreb, Rijeka, Osijek and Split) performed their daily work in gloves!



Excellent cooperation with physicians is also reflected in the DeSci-pher project - a project of EUSTAR funded by the EU which was launched on World Scleroderma Day. Presentations of the project through posters and leaflets, as well as interviews with physicians resulted in the inclusion of physicians from four clinical centers in this long-term observational project. Patients were also informed about the project and are continuously encouraged to cooperate with doctors on this project.

This year HUOS began to educate health professionals in regional spas about symptoms and problems that scleroderma patients face. Education that we offer includes experts and patients as speakers, and lecture topics are: physiotherapy for scleroderma, wound care (digital ulcers), pain and psychological aspects in scleroderma. We use the opportunity to present our patient organization and the DeSci-pher project so that newly diagnosed people will be able to get information and support..

We are proud that the association has employed a physical therapist who is available to all members of the association and greatly raises the functionality and quality of life for patients. For the third World Scleroderma Congress to be held in Rome, as a part of the Patient Programme, we are preparing a workshop for breathing exercises in a good posture.

HUOS will continue to be active for the benefit of scleroderma patients in Croatia and abroad!

Sanja Roškar, The Croatian Society For Patients With Scleroderma (CSPS)



Eumusc.net is a project initiated by EULAR and undertaken with the support of the European Commission and for the first time, thanks to the methods and tools developed with this initiative, it will be possible to assess, monitor and benchmark the burden of rheumatic musculoskeletal diseases (RMDs) as well as the quality of care that people with RMDs receive in EU countries. This information will allow countries to set goals for improvements in the provision of health care as well as to measure progress towards equity of care, write Prof. Anthony Woolf and EULAR President Prof. Maurizio Cutolo in the foreword for the conference.

The conference brought together representatives from:

- ◇ EU institutions
- ◇ member state institutions
- ◇ research organisations
- ◇ medical and health professional associations
- ◇ patient organisations
- ◇ research funding bodies
- ◇ social service providers

The initial part of the day took place in the EU Parliament where speakers from EULAR, the EU commission, Ministry of Health in Lithuania, Association of People with RMDs in Crete, WHO representative to the EU and eumusc.net, all spoke about the need for standards of care for people with rheumatic conditions in the EU. Anthony Woolf, eumusc.net Scientific Coordinator, explained that one of the many outcomes of the project was standards of care for two musculoskeletal conditions: osteoarthritis, the most common joint disorder which accounts for more disability among the elderly than any other disease; and rheumatoid arthritis, the most common inflammatory disease of the joints. The report covers all aspects of musculoskeletal conditions (MSC). Even though it was hard to find anything on connective tissue diseases, we were assured that we had been included, however because osteoarthritis and rheumatoid arthritis are the most common types of RMDs, the findings in the report look specifically at these two conditions comparing comparative data throughout the EU member states.

MSCs are one of the most common causes of severe long-term pain and disability in the EU and lead to significant healthcare and social support costs. To read the full report or the summary, visit www.eumusc.net. In the afternoon, delegates joined break-out workshops at the Thon Hotel, a short walk from the European Parliament. The purpose was to take one of the Standards of Care and look at barriers to successful implementation of each standard; these will of course differ between member states but our group's statement for discussion was "People with Rheumatoid Arthritis should be assessed regularly to ensure disease control". The main barrier might surprise you: it was the lack of rheumatologists who understand RA and would understand the importance of regular assessment. We were also trying to explore ways around the barriers as due to the lack of monetary funds within the EU we decided that just demanding more rheumatologists was not really an option so we explored other ways which included specialist nurses and other health practitioners who would assist the consultants in their already busy clinics.

During the final part of the day, Dr. Isabel de la Mata, Principal Advisor, Public Health and Risk Assessment, European Commission, suggested that we look for other areas regarding funding rather than just concentrate on the health commission, such as the commission in charge of social security, for example.

Throughout the day, there were many references to prevention and physical activity which is important for prevention for some types of RMDs, but also for managing conditions once diagnosed, and physical activity was pivotal. If in doubt regarding your own personal exercise capacity, always consult your health professional whilst trying to stay as fit as possible.

Kim Fligelstone reporting from the Chronic Diseases and Health Care Delivery 2020: The Challenge of Rheumatic and Musculoskeletal Diseases Conference in Brussels, European Parliament and Thon Hotel EU, Brussels, 17th October 2013.



The DeSScIPHER Project

"To decipher the optimal management of Systemic Sclerosis"



On April 1st 2013, the observational trials of the international EU-funded research project “DeSScIPHER” began. It is currently the largest research project ever for systemic sclerosis.

About Systemic Sclerosis (SSc)

SSc is a prototypic disease characterized by autoimmunity, fibrosis and vasculopathy. Among autoimmune rheumatic diseases, SSc is one of the most incapacitating and life-threatening entities and associated with a high loss of life expectancy. With a prevalence from approximately 7/million to 489/million of the general population, systemic sclerosis is an orphan disease.

Aside from the clinically prominent thickening of the skin and the development of digital ulcers, it is also a multi-organ disease affecting the connective tissue of the skin and almost all internal organs, driven by alterations of both the immune system and the microvasculature. The progressive deterioration of internal organ function and integrity, particularly of the lungs, heart, kidneys and gastrointestinal tract, as well as the frequently underestimated polyarthritis result in a high morbidity and mortality ranging up to 30% over five years. The juvenile-onset form is rarer than the adult-onset form and less than 5% of SSc patients develop the disease in childhood, usually around nine years of age. In contrast to the majority of other rheumatic and immunologic diseases, therapeutic options for SSc patients are much more limited, and neither truly disease-modifying drugs nor orphan drugs are available at present.

About the Project DeSScIPHER

DeSScIPHER is the short form for the project title **“To decipher the optimal management of systemic sclerosis”**. The aim of this EU-funded international FP7 research programme project is to improve clinical practice in the management of systemic sclerosis, for which thus far only off-label treatments are available. Over a three-year period, building upon the expertise of an established, pan-European, multidisciplinary and experienced consortium combining physicians, biostatisticians and biologists with long-standing expertise in the field of SSc (the EULAR-based EUSTAR group), DeSScIPHER will provide a systematic, integrated approach to the disease. This approach is primarily based on five observational trials, which will be conducted over a period of at least two years. These observational studies are designed to cover different evolutionary phases of the disease from early functionally relevant manifestations such as digital ulcers (observational trial 1) and hand arthritis (observational trial 2), to more severe organ manifestations such as interstitial lung disease (observational trial 3), pulmonary hypertension (observational trial 4), and also severe heart disease (observational trial 5).

Unlike interventional studies, which may compare, for instance, a novel drug vs. placebo, observational studies investigate the effects of treatment in real-life care of patients by monitoring the disease and its organ-manifestations very closely but without exerting an active influence on the treatment. The patients stay on their individual medication in routine clinical practice, and this medication is only changed according the patients' individual medical needs but not for the purpose of participating in the observational trial.

The specific objectives of the DeSScIPHER project are:

- To improve clinical practice in the management of SSc for both adult and juvenile patients;
- To facilitate earlier detection and prevention of SSc and its organ manifestations and subsequently initiate disease- or organ-specific treatment;
- To improve both quality of life and morbidity/mortality in SSc by addressing functional impairments caused by digital ulcers and hand arthritis as well as life-threatening organ complications due to interstitial lung disease, pulmonary hypertension and severe heart disease;
- To develop and validate a reliable algorithm for detecting organ manifestations of SSc at an early stage in adult and juvenile patients at risk;
- To compare outcomes of prevention and treatment regimens in SSc to define appropriate outcome measures for SSc trials;
- To evaluate the efficacy and safety of off-label treatments currently used to target the main disabling and life-threatening organ manifestations of SSc;
- To contribute actively to the development and rapid dissemination of national, European and international guidelines for the diagnosis and management of adult and juvenile SSc.

The role of patients and the cooperation with the Federation of European Scleroderma Associations aisbl. (FESCA) in the project

Patients have a vital interest in getting better care. Due to their severe disability and clinical symptoms such as fatigue and incapacity, they often have no voice that is heard by politicians and other stakeholders in the field of patient care, and their disease lacks adequate public attention. Due to the orphan status, the severe disability, the number of comorbidities such as malnutrition and depression, and the prognosis of the disease, the number of patients joining patient organizations is limited and therefore, awareness at present is not as high as needed. To make the guidelines and project results readily available, the project will include SSc patients and their representatives throughout the entire dissemination process.

The Federation of European Scleroderma Associations aisbl. (FESCA) is one of the main partners in this project. FESCA was founded in 2007 and is registered as a charity in Belgium, with a Board recruited from five different EU countries. It is an umbrella group of 23 national scleroderma patient support and advocacy organizations in 18 European countries. Its mission is to provide information to people with SSc, increase awareness on an international level, and advocate for equitable treatments for people with SSc throughout Europe.

FESCA's objectives include encouraging the active involvement of politicians, working with doctors to secure earlier diagnosis and better treatments, and creating greater awareness of SSc so that those who suffer from it can access proper, equitable care. For this purpose, FESCA facilitates collaboration among national associations to share ideas and projects, and works towards the evolution of a political, social, and medical environment that facilitates the achievement of the FESCA vision. (www.fesca-scleroderma.eu)

The advantage of FESCA is that this umbrella patient organization operates through regular involvement of patients and their relatives in many formats, including the international World Scleroderma Congress and the EUSTAR training course. The role of FESCA in DeSSciphier is to encourage the active involvement of policy-makers. Working with doctors to secure earlier diagnosis and better treatments, FESCA will also contribute to creating greater awareness of SSc, so that those who suffer from it can access proper and equitable care. Since SSc is a prototypic disease for autoimmunity, vasculopathy, and fibrosis, patients with related diseases will also profit. Results and guidelines will be translated into all national languages and will be disseminated to physicians and patients by means of annual “National SSc Days” at key centers of the DeSSciphier partners, with interactive presentations on selected topics of SSc. The results and guidelines will also be presented at national conferences and other events held every year on International Scleroderma Day (June 29th). Furthermore, patient information brochures will be prepared and disseminated to hospitals, healthcare centers and general practitioners via mailing lists of national medical societies.

DeSSciphier consortium

There are 14 partners in this project: Justus-Liebig-Universität Gießen/Germany (project coordinator), Universität Zürich/Switzerland, Università degli Studi di Firenze/Italy, Seconda Università degli Studi di Napoli/Italy, Université Paris Descartes/France, University of Pécs/Hungary, Universität Basel and Felix Platter Spital/Switzerland, University College London/UK, Charité - Universitätsmedizin Berlin/Germany, University of Leeds/UK, New win AG/Switzerland, Juvenile Systemic Sclerosis Working Group of the Pediatric Rheumatology European Society, the agency NOVAMEN, and Federation of European Scleroderma Associations aisbl..

Participation in the DeSSciphier project – contributing centers

Originating from the leading DeSSciphier partner centers, now every EUSTAR (www.eustar.org) centre and all other SSc patient care centres can include their patients. Contact details of currently participating centers are provided on the homepage. If a centre has not already contributed to DeSSciphier, and you as a patient wish to participate, just ask them if they will become a contributing centre. If a patient wants to directly contact the central coordination centre of DeSSciphier for help, the email address is dessciphier@kerckhoff.med.uni-giessen.de.

As FESCA is also a founding DeSSciphier partner, the national FESCA representative or your local SSc patient association can provide you with additional information. (www.fesca-scleroderma.eu)

More information about DeSSciphier

A homepage (www.dessciphier.eu) has been created, with a special section on information for patients. This homepage will be expanded over time, but you will already find a patient information brochure with basic information about the observational trials.

*Beata Garay Toth
Vice President
FESCA*

2014 World Congress



The Third Systemic Sclerosis World Congress is soon upon us! The Congress will take place in Rome from the 6th-8th February 2014 at the Ergife Hotel, in the area of Rome behind the Vatican.

There will be two congresses held at the same time. There will be a congress for doctors, and another for patients. The patient congress will be a two-day programme and anyone is welcome to attend: this could be people who have scleroderma, their friends, families, or anyone else interested in learning more about scleroderma.



The Patient Programme for the Third Systemic Sclerosis World Congress will consist of interactive sessions of lecture and discussion, with consultants and patients speaking on topics including:

- Why did I get scleroderma and will I be cured?
 - The lungs—why is breathing so difficult?
- What can I do to help digestion and nutrition?
 - What can be done about digital ulcers?
- Transplants of different kinds—are they for me?
 - Face, hand and breathing exercises
 - Sexuality and pregnancy
 - Dentistry in SSc
 - New treatments
 - Carers and family members
 - Fatigue and how to deal with it
 - Useful tips for daily life
 - How can I cope emotionally?
 - Make-up and dermatology

Two exclusive sessions will address small-group needs: Men with Scleroderma and Juvenile Scleroderma. The patient congress will also include a round-table networking meeting for leaders of patient groups.

The patient congress opens on Thursday afternoon 6th February and runs from 9.00 to 16.00 on Friday 7th February, and 9.00 to 13.30 on Saturday 8th February. The FESCA AGM follows directly after the congress on Saturday afternoon and continues on Sunday morning 9th February.

The cost of the registration fee for the patient congress is Euro 35, VAT included. If you require simultaneous translation, there will be an additional fee of Euro 10, VAT included.

The registration fee includes:

- > Congress kit
- > Access to the patient congress sessions
- > Coffee breaks and working lunch as indicated in the programme.

For online registration, visit the AIM website: [click here](#)

You can also register by completing the paper registration form which you can download from the AIM website: [click here](#).

You should then send it to:

AIM Group International – AIM Congress - Rome Office
Via Flaminia 1068 – 00189 Rome, Italy
Tel. +39 06 33053.1
Fax +39 06 33053.249
E-mail: ssc2014.reg@aimgroup.eu

For information on booking hotels in Rome, please visit the AIM website: [click here](#)
The congress will be held in the Ergife Hotel, with the possibility to also stay in the Ergife or at an inexpensive hotel that is walking distance away. Both can be booked through the congress website upon registration.

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.

Federation of European Scleroderma Associations (FESCA)

International Non-Profit Association

Registration No: FOJ 15454

Email: info@fesca-scleroderma.eu

Website: www.fesca-scleroderma.eu

Registered address:

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

President: Ann Tyrell Kennedy, Ireland
anntkennedy@gmail.com

Vice-President: Beata Garay-Toth, Hungary
gtbea@yahoo.com

Co-Secretaries: Catherine Vandenbosch, Belgium
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Treasurer: Despo Charalambous Demetriou, Cyprus
ddcooper@cytanet.com.cy

Newsletter Editor: Susie, U.K.
susie@sclerodermasociety.co.uk

Member Organisations

Belgium

League for Chronic Inflammatory
Connective Tissue Diseases
<http://www.cibliga.be>
secretariaat@cibliga.be

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

Croatia

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

Cyprus

Cyprus League Against Rheumatism
<http://www.rheumatism.org.cy>
cyplar@cytanet.com.cy

Denmark

Danish Scleroderma & Raynaud's Association
<http://www.sklerodermi.dk>
info@sklerodermi.dk

Finland

Finnish Scleroderma Association
<http://244846.edicypages.com>
marjo.makela@ebaana.net

France

French Scleroderma Patient Organization
<http://www.association-sclerodermie.fr>
info@association-sclerodermie.fr

Hungary

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

Ireland

Raynaud's & Scleroderma, Ireland
<http://www.irishraynauds.com>
info@irishraynauds.com

Italy

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

Italian Association to Scleroderma Fight
<http://www.ails.it>
ails-an@libero.it

Italian Groupe for the Struggle
to the Scleroderma
<http://www.sclerodermia.net>
gils@sclerodermia.net

Pugliese Association Arthritis Patients
<http://www.apmar.it>
info@apmar.it

Germany

Patient Organization for Scleroderma
<http://www.sklerodermie-sh.de>
sklerodermie@t-online.de

Norway

The Norwegian Rheumatic Organisation
<http://www.sklerodermi.no>
sklerodermi@revmatiker.org

Poland

Pro Rheumate – Group of Scleroderma Patients
<http://www.twardzina.pl>
bealew23@wp.pl

Portugal

The Portuguese League Against
Rheumatic Diseases
<http://www.lpcdr.org.pt>
lpcdr@lpcdr.org.pt

Spain

Spanish Scleroderma Association
<http://www.esclerodermia.org>
a.e.esclerodermia@wanadoo.es

Sweden

The Swedish Rheumatism Association
<http://www.reumatikerforbundet.org>
info@reumatikerforbundet.org

Switzerland

Swiss Association of Scleroderma Patients
<http://www.sclerodermie.ch>
info@sclerodermie.ch

The Netherlands

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

U.K.

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

The Scleroderma Society
<http://www.sclerodermasociety.co.uk>
info@sclerodermasociety.co.uk