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## SOME DATES FOR YOUR DIARY:

Training course in Scleroderma for Rheumatologists, Belgrade, January 27-30, 2011

FESCA Annual Meeting, Budapest, March 31-April 2, 2011

EULAR Congress 2011, London, May 25-29, 2011

Second World Scleroderma Congress, Madrid, February 2-5, 2012



French-speaking Belgium celebrated  
World Scleroderma Day with balloons



## EULAR ROME 2010

Rome is a destination that holds great allure. But attending a congress in a beautiful city has little resemblance to visiting it on holiday, and this summer's EULAR congress was no exception. Rome's largest convention hall is located far west of the city, a giant complex of halls spread out like airplane hangars in an expanse of empty fields, and this, the major conference that deals with muskuloskeletal and rheumatic diseases, brought over 15,000 medical people to Rome to fill it. It was a busy time.

The weather of course, is wonderful in June, and the delightful thing about these arid concrete hangars in Rome is that they are connected by sunlit walkways in the fresh air. For the FESCA members working at our stand at EULAR, the glorious hot weather was a great gift. All those volun-

Of interest to all who visited the stand were the new SO RARE cards that we launched in Ireland on Scleroderma Day. Everybody took a card. It was pocketed when other leaflets were left behind, because it demonstrates both what a Raynaud's attack looks like, and what the early symptoms of scleroderma are. It could perhaps become the theme of next year's FESCA campaign for Scleroderma Day.

Running the stand was the responsibility of GILS representative Grazia Tassini, who lives in Rome, and she was wonderful. A full team covered the stand at all times, with never fewer than two people; it was beautifully decorated with posters and leaflets from many of our members, and it looked most professional. It was centred in the "village" of adjunct agencies in the exhibition hall.

teering at the stand suffer from Raynaud's. Many of us have gone home from past congresses with pain and ulcerations from the cold. But this time, the warmth was a blessing. We could even eat outside at tables in the sun. Nobody developed ulcers.

The stand was buzzing with activity every day, as doctors and allied medical professionals visited and collected information. The EULAR (European League Against Rheumatic diseases) congress is mostly for doctors involved with rheumatic diseases, with ancillary programmes of lectures for other professionals, and a separate programme for patient organisations, who are grouped under the title PARE. Most specialist doctors are now well aware of the value of the patient organisation in disseminating information to people

with disease, and the doctors coming to our stand were asking how their patients could contact us, how people in their country could start up their own patient organisation for those who suffer from scleroderma, or how an existing group could join the umbrella group FESCA. We were impressed by the determination of many doctors to help patients start self-help groups. Since they came from all over the world, English was usually the language of communication. This meant that those of us fluent in English were particularly busy. We had doctors from India, Iran, Israel, and Singapore as well as all EU countries and the Americas. The stands were open from 9 until 5 pm, and lectures and meetings ran concurrently from 7 in the morning until 7 at night. Doctors really do work hard.





In addition to running the stand, FESCA is responsible for giving talks at the EULAR congress. The official language is English, and the topics can either be determined by EULAR or PARE upon invitation, or suggested by a FESCA representative in an early proposal. We have given talks on the patient perspective regarding scleroderma treatment, designed to help doctors to understand the disease from the other side; on how to create and develop a patient organisation, designed to assist new groups to avoid pitfalls and define useful paths to follow; and on what the role of the patient organisation is, in the current medical climate. Talks run concurrently throughout the convention, with major medical lectures drawing audiences of 700 or more, and the PARE patient programme usually bringing in 50 to 100 people.

Between sessions, the four FESCA Board members had a lot to do: meeting with representatives from pharmaceutical companies who might provide funding, talking to doctors who can assist with individual programmes, and developing relationships with other patient organisations who can be helpful in the future. If ever there is a moment, the stands are full of fascinating information about new treatments, medications, gadgets, and research studies. In addition, some 1,600 abstracts on diseases of the connective tissue, locomotor, and musculoskeletal systems are put up as posters, for view and discussion. Luckily, most stands offer food or beverages, which in Rome are of a very high standard, as you might imagine, so we kept our strength up and enjoyed the work.

I hope that next year several FESCA member representatives will be able to come to London for the EULAR congress, May 25-29, 2011. If you submit an abstract for a poster now, and at the same time make a submission for a travel bursary if the abstract is accepted, then your way will be paid. All information about this is on the EULAR website. The deadline is soon! In London our English member groups will be in charge of running the FESCA stand for 2011, and the Scleroderma Society's Kim Fligelstone will be in charge. We are counting ourselves lucky that the EULAR congress does not coincide with the Royal Wedding!

Ann Tyrrell Kennedy,  
President FESCA





## WORLD SCLERODERMA DAY 29 JUNE 2010

Some accounts of how several member countries celebrated Scleroderma Day.

### DENMARK

In Denmark we had a conference held at Bispebjerg Hospital in Copenhagen. And the department of dermatology was giving lectures of news from research, diagnosis and treatment at the hospital. It was a very good and informative conference and around 150 patients and families were attending.

The first lecture was introduction to video nailfold capillaroscopy attached to a computer. This can enlarge the capillaries many times and show even the small-

est blood vessels. With this machine it is a bit easier to prevent who will develop ulcers and who will not.

This is a new method Bispebjerg is doing in cooperation with Aarhus Hospital.

Next lecture was different ways in treating ulcers. The hospital is registering the ulcers in the Digital Ulcer Outcome /DUO - a cooperation with other countries (UK??) - and the goal of this registration is to gather information and share information of how to treat the patients even better. Different ways in treating ulcers was shown on slides and can be

found on the Danish Scleroderma & Raynaud's website.

Then we had a "walk through" of the Six-minute walk test. A doctor told of laser treatment of teleangectasia. When to do laser and when not.

A young doctor told of her research project, a biomedicine project. To find a connection between biomarkers and scleroderma. In same way as the finding of biomarkers in arthritis and osteoporosis.

The conference was ended with information of EUSTAR and what this means for the patient.

FESCA was also mentioned.

All in all few hours of good information and with 150 attendants the Danish Scleroderma & Raynaud Association was very pleased with the conference.

Annelise Rønnow



### CYPRUS

The 1<sup>st</sup> event was a Press Conference for the Media on the 23<sup>rd</sup> of June in order to inform journalists that the 29<sup>th</sup> of June is dedicated to Scleroderma and of course to raise awareness among the public. The Press Conference was supported by the Cyprus Rheumatology Society and the participation of the President of the Society Dr. Paraskevi Charalambous that also spoke to the media about Scleroderma. Along with Dr. Charalambous at the Conference spoke the Vice-President of the Cyprus League Against Rheumatism Mrs. Iosifina Iosif Stylianou and the General Treasurer of the League Mrs. Despo Charalambous which is also the coordinator of the Group of people with Scleroderma. The event took place at the offices of the Cyprus League and

had a lot of coverage from TV journalists and newspaper journalists as well. Newspapers also published a number of articles about Scleroderma and prior to the Press Conference in order to support our events. Press packs were given to the media containing information about the World Scleroderma Day, Scleroderma and the event that the League was preparing for people with Scleroderma.

After the event our League sent a press release and photos from the Press Conference to media so that they could publish them.

The 2<sup>nd</sup> event had as a goal to bring people with Scleroderma together and inform them about the new developments but also for them to meet other people with the same problems and needs and in order to create strong ties between them.

The event took place on the 28<sup>th</sup> of June at 7.30 p.m, we invited all the people with Scleroderma registered in the Leagues database and they were asked to bring their spouse, or a friend, or any family member with them so that it would make them feel more comfortable. During the event a Rheumatologist talked Dr. Savvas Psarellis about the new developments and how things are at this point and also a Nutritionist talked Mrs. Thaleia Avraam about the diet that people with Scleroderma must do along with some tips on what foods are good and bad. The event was very successful and people with Scleroderma and their accompanied person really enjoyed it and they had the opportunity to mingle with others. 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 programmes and shows and also different articles were written in a number of Cypriot newspapers. Also posters were produced and placed to a number of spots like hospitals and pharmacists in order to inform the general public. Also a poster stand was created using the sunflower logo of Fesca.

Maria Matheou,  
Director of CYPLAR



Despo Charalambous



## UNITED KINGDOM, SCLERODERMA SOCIETY

June 29 is World Scleroderma Day. It's the day that the Swiss painter, Paul Klee, died, and now Scleroderma organisations all over the world use this day to try and raise awareness of our unique and rare condition. And that's not easy in a world already full of competing messages. This year we decided to target a number of medical organisations in central London as well as Parliament and, to a lesser extent, the public as a whole. A crack team comprising Kim, Chris Nickerson, Fiona Robertson and I visited a grand total of 16 different locations ending up at the House of Commons. At each of the places we visited we left information about scleroderma, pens (always very popular!) and bookmarks (less popular, but more informative). Where possible we met with representatives of the organisations we visited. To travel between locations, we went by rickshaw which have become a bit of a London tradition in the few years they have been around. In total we hired 3 rickshaws which were decorated in the colours of the Scleroderma Society and adorned with matching balloons just to make them that little bit more eye-catching. The branding obviously worked... one of the many highlights of the day was the convoy being flagged down by someone with scleroderma on Gower Street (and if that was you and you are reading this then please contact Kim or Richard as we'd love to hear from you). Even a few weeks later, when the rickshaws were still running round London with our colours, we got a call from someone who had seen them and wanted to know some

more information....

Just as important as the rickshaws were the 3 riders. Arjun, Alex and Jacob: what would we have done without you! They were fantastic. They threw themselves into the day and when they weren't peddling us round town they were handing out leaflets and pens and generally picking up the slack when the rest of us began to flag.

While the concept of being ridden round London in a rickshaw might sound relaxing it has to be said it had its hairier moments. What do you do when you're late to meet an MP and Regent Street is blocked? Squeeze between a few buses and then use the wrong side of the road of course.....

So where did we go? It was quite a route in the end. We started at the British Association of Rheumatologists and ended up at the House of Commons. In between we visited 2 health centres (Finsbury Health Centre and the Museum Practice), 2 research bodies (the Wellcome Trust and the Medical Research Council), 2 associations (the British Association of Dermatologists (BAD) and the British Medical Association) 3 Royal Colleges (Nursing, Physicians, Paediatrics and Child Health) and a physiotherapy clinic.

At the Royal College of Physicians we were lucky enough to be met by the President, Professor Sir Ian Gilmore. We also met the chief executive of the British Society of Rheumatologists, Samantha Peters, the director of ARMA, Ros Meek and the deputy chief executive of the BAD, Catherine Hanaway. Dr Agrawal and the team from the Museum Practice also met us outside the British Museum.

Somehow in the middle of it all

we managed a quick sandwich stop in Carnaby Street where of course it was the crack team that needed a sit down while our drivers continued to hand out bookmarks and pens to those that passed...

At the very end of the day, and half an hour late, we managed to park outside the Houses of Commons where we had arranged to meet Julian Smith, MP for Skipton and Ripon. Julian like so many people did not know about scleroderma but after being bombarded with information we'd like to think he knows a little bit more now....

So did we fulfil our objective? It was certainly a long and tiring day but with all these things it is hard to know how effective they have been. Looking back at the locations we visited, the information we handed out and the interest the rickshaw convoy generated we are sure that we did indeed raise awareness of our rare and unique condition...

Susie Hoare





## INTERNATIONAL FORUMS FOR SCLERODERMA

Scleroderma is a lonely disease, not only because it is very rare, but because the activities of those who have it are often limited, and travel difficult. Very little research into the disease had been done until recent years, and those with this disabling disease continue to have great difficulty in accessing information about diagnosis and treatments. So the loneliness is magnified.

The more forums we can encourage for scleroderma-talk the better. The Federation of European Scleroderma Associations, or FESCA, was founded to help organisations throughout Europe to cross the barriers of language, differing medical and social systems, lack of awareness, and inaccessible medical information. Nationalism has no place in the realm of information-dissemination.

The first World Scleroderma Congress was held in Florence in February 2010, and the second will be held in Madrid on February 2-4, 2012. The first European Scleroderma Day was held on June 29, 2009, followed by the first World Scleroderma Day on June 29, 2010. But we still need more ways to spread information and awareness.

Talk breeds talk. We need to reach people where they are, and sometimes this is not through the traditional forums of conferences, meetings, or even national websites. Sometimes it is through social networking. Many good sites exist where information can be sought, and some support group websites now offer blogging opportunities. On Facebook, for instance, a Danish member of FESCA has created a closed group, where Danes, Norwegians, and Swedish people can

join in discussion; membership must be approved by the administrator. After only three years, it has 239 members. They understand each others' languages, that is the point. The languages of the three countries are very similar and each person can write in her or her own language. Those from other countries like Finland, where most people learn Swedish, can also join the group, as can emigrants worldwide. Newly diagnosed, the Danish founder of the group wanted to find others with the same disease as she had. At the time there was no Danish association—it was founded a few months later—so she was frustrated and needed to scream out her frustration to others who would understand. As yet, Norway, Sweden, and Finland do not have their own patient support organisations for scleroderma.

FESCA has received requests from countries around the world for support and information, countries as disparate as the Philippines, Iran, Egypt, Argentina, and India. The opportunities offered by the internet seem to be an excellent solution to the lack of local support groups. Some existing support groups—like a group of CREST members in Germany—have never actually met, but correspond by email. Internet sites can be open or closed. Some blogging sites are huge, like scleroderma.org.

Twitter can also be used for spreading the word. The Scleroderma Care Foundation of Trinidad & Tobago is very active on Twitter, for instance.

These global groups can break down the boundaries between countries and create a wider world network of people with scleroderma. We can meet others where they are, inside warm rooms with their laptops, instead of relying on cold meeting halls thousands of miles apart. In an ideal world, we can do both!

Ann Tyrrell Kennedy,  
President FESCA

**FESCA is now working  
on developing its own  
Facebook page**

**The next World  
Scleroderma Patient  
Congress will be held  
in Madrid, Spain, on  
February 2-4, 2012**



### "THE SNOWMAN" BY JO NESBO

Do you like reading crime-books? Have you read the Norwegian writer Jo Nesbo's bestselling book "The Snowman"? If not - read on. We give you a teaser that might want you to read the book. One of the characters in "The snowman" has scleroderma. But you must only read it as a novel, and nothing else.

It is book nr. 7 starring Detective Harry Hole, who works for the Oslo police department. He is very smart but a bit introvert, does things his own way and doesn't always communicate well, has some series issues with alcohol, and is not very well liked by colleagues in the Oslo police force. But he is their best investigator.

In "The Snowman" Harry receives a letter with the signature "The Snowman". Along with this letter Harry discovers a link to wives and mothers who have gone missing over the years. There is a previously overlooked pattern in the data: Many married women have gone missing on the day when the first snow falls. It is clear that Harry and his men are dealing with a serial killer who has been very quiet about his crimes but now wants to show himself to Harry. For the first time a missing head is placed on top of a snowman.

The killer makes Harry feel that he is being played with. That he has become a pawn in a brutal and deadly game. And Harry is being played with - before the game is over, the killer will drive him to the brink of insanity.

The rights for the book have now been sold to the British Working Title Films. When it will hit the big screen we don't know.

Annelise Rønnow



**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](http://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](mailto:info@fesca-scleroderma.eu)

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

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