

Hello dear FESCA friends,

It is nearly the very end of 2019 and it has been a hard year for many. Like everything else, scleroderma has its ups and downs, but now we have a fresh new year to look forward to, and the sun is shining. Your hard-working Board send to you all the very best wishes for joy and good health in the coming year. I am writing this instead of Annelise, who has not been well, and we all look forward to when she can join us again.

We have been concentrating lately on the development of our World Scleroderma Congress, which will take place in Prague on March 5<sup>th</sup> until March 7<sup>th</sup>. The challenge for us was that although we have been growing in our number of membership countries, we do not yet have a Czech Republic organisation for scleroderma patients. But we have met a lovely enterprising woman who is leading the way to complete this challenge. You will meet Michaela at the congress, the arrangements for which she has been helping to accomplish.

On Thursday March 5<sup>th</sup> we have our AGM in the morning. Then at 4pm we will hold a global patient leaders' meeting preceding the official Opening Ceremonies of the congress. A surprising new, wide-ranging project will be announced at this roundtable meeting. Then on Friday and Saturday, we will enjoy one and a half days of workshops and lectures and networking. The programme is full and we look forward to leading you through it. This year, we are giving added focus to young people who have scleroderma and hope that many are able to attend.

Certainly Prague is a wonderful city to explore, and we have kept down the registration price for the congress to enable as many as possible to come. Live-streaming will make it possible for those who cannot attend to watch and listen at home.

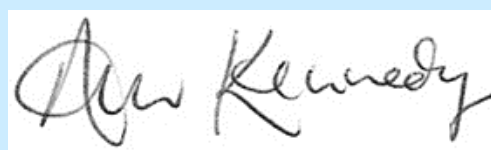
In June 2019 we celebrated World Scleroderma Day with a wonderful campaign led by Serena Mingolla,



some descriptions of which follow in the next pages, and in 2020 Helena Gaspar of Portugal is leading us into a new campaign. The campaign for 2020—doesn't that sound futuristic! It seems so long ago we created FESCA. We have accomplished a great deal.

There are many new treatments for scleroderma available now, or on the horizon, and the future is promising indeed. We have been working with new partners to achieve successful therapies, and one of these partnerships has resulted in an award for patient engagement, to be given in February 2020 at the EURORDIS Black Pearl Rare Disease Day ceremonies, to Boehringer Ingelheim. The award recognises this company's commitment to collaborative and comprehensive engagement with patient organisations. In forming, with FESCA, a Community Advisory Board in accordance with EURORDIS principles, BI committed its efforts not only to patients' medical needs, but also to barriers to access, and to the social context of living with rare disease. We are proud to be associated with this work.

I wish you all a wonderful, joyful, healthful year. May 2020 shine brightly for you.



# Edgar Stene Prize 2020

The title for the 2020 Edgar Stene Prize essay competition is “Being a person with a rheumatic or musculoskeletal disease (RMD) - How my voluntary work benefits me”.

The following information is provided by EULAR: “We invite people with RMDs to write about their personal experiences. We all want to live life to the fullest and independently and work is an essential part of our life. But for many people with RMDs it cannot always be a paid employment or a fulltime job due to the challenges caused by the disease. Voluntary work can be equally fulfilling and being a great opportunity to be contributing to society as essential part of it. Thankfully this has also been noticed by the society in recent years and volunteering has become more positively acknowledged and appreciated in many countries. We would love to hear why people with RMDs are volunteering, their motivation and what they are doing. Also, what experiences they have made in their country, what challenges they face but most of all about the personal benefits related to voluntary work.

As in the past, we encourage our national EULAR member organisations of PARE to organise national competitions for people with a rheumatic or musculoskeletal disease (minimum 18 years of age). Competitors should be invited to submit an essay not exceeding 2 pages (A4) in their

own language to their national EULAR member organisation of PARE. The deadline for the national completion will be set individually by each national organisation. Anyone who would like to submit an essay should get in touch with their respective national EULAR member organisation for further information. Each national jury should select and submit the best entry from their country (only one entry) by email to the EULAR Secretariat by 20 January 2020. A more detailed outline of the rules is attached to this letter for your information. Please note that these have to be fully adhered to, as applications which are not complete will not be accepted by the EULAR Secretariat. A EULAR Jury will select the 2020 Stene Prize winner to be announced by 15 March 2020. The jury’s decision is incontestable. Information about the 2020 EULAR Jury will be posted in the coming months on [www.eular.org](http://www.eular.org) The Stene Prize winner will be invited to attend the Opening Plenary Session of the EULAR Congress in Frankfurt and is awarded a prize of € 1 000. EULAR provides the winner with travel to Frankfurt and hotel accommodation for up to 4 nights as well as with an invitation to the EULAR Congress Gala Dinner.”

Read more on the website: [https://www.eular.org/pare\\_stene\\_prize.cfm](https://www.eular.org/pare_stene_prize.cfm)

# World Scleroderma Day, Switzerland



SVS Schweizerische Vereinigung der Sklerodermie-Betroffenen  
ASS Association Suisse des Sclérodermiques  
ASS Associazione Svizzera della Sclerodermia

On the occasion of the 10th World Scleroderma Day, we organized a « conference-friendship day ». An exchange between all members of different associations, such as scleroderma, lupus, fibromyalgia, rheumatism. The goal is to help all sick people because:

## Hand in hand, scleroderma will not take my smile!

The "self-hypnosis" conference given by Mrs. Smit, a pain management nurse, was captivating. Indeed, during chronic pain, self-hypnosis can be a great help that everyone can practise at home after taking a few lessons.

After sharing our lunch, we went for a nice walk together in a small tourist town. Friendship is really important and spending a day together creates strong relationships. As winter approaches, scleroderma forces us to do fewer activities outdoors or for some of us to stay home for long months.

We will keep a wonderful memory of this beautiful day.



# World Scleroderma Day, Hungary



This year again we had an integrated campaign all over Hungary for World Scleroderma Day based on activities that were developed centrally by FESCA – “Scleroderma will not take my smile – The whole word of support”. We raised awareness with events in three locations: Pecs, Szeged, Budapest with member involvement.

We organised interesting awareness programs outside for our members regionally in three cities. The main topic beside *Scleroderma cannot take my smile* was to celebrate the 10th anniversary of World Scleroderma Day. As it is held on the day of the death of Paul Klee, the famous Swiss painter, we organised our awareness raising activities around the main museum centres.

In Budapest on the 29th June, in the most popular and busy part of the city, in the Buda Castle region, we set up a booth, our roll up and distributed leaflets. Then we had a museum visit in a photo exhibition FORTEPAN which was followed by a club meeting with members talking about old family photos in one of the art room of the National Gallery.

In Szeged on the 29th June we organized a similar event but here the awareness raising was on the main city square of Szeged where many people got together celebrating the city's founding. Here we also placed a stand with roll-up and distributed the leaflets. They also went for a museum tour.

In Pecs on the 29th June the busy old town was selected as the awareness raising place with roll up and leaflet distributing and then an interesting tour was given for members in Early Christian Necropolis from the 4<sup>th</sup> Century.

Beside the main events in the cities we placed twenty WSD posters in clinics and centres. At five national clinics, in rheumatology and dermatology departments on corridor walls (Debrecen, Pecs, Szeged Clinics of Rheumatology and Budapest Dermatological Clinic), we placed roll ups for awareness. During WSD regional events in three cities – Szeged, Pécs, Budapest and leaflets we distributed 600 pieces in total in cities and in clinics.

In order to boost awareness at national level we used on- and off line PR articles: in two women's magazine with the biggest circulation and in the most read patient information website [https://www.webbeteg.hu/cikkek/autoimmun\\_betegseg/24036/scleroderma](https://www.webbeteg.hu/cikkek/autoimmun_betegseg/24036/scleroderma)

Our last main effective tool of the campaign was the online media and social networks: Facebook, Twitter and Instagram and the website of our association. Here we communicated the new WSD video film, banner, posts and photos about the events. The stats: the FB page of our association, and on our website - 550-600 people reached, 139 engagement, 17 shares, WSD banner: on our FB page, website, Twitter, Instagram, Facebook post: 18, out of this the poster reach is 1136, engagement 50.



*In front of the National Gallery at the Castle Hill, Budapest*



*City Square, Szeged*



*Pecs, in front of the Necropolis*



## World Scleroderma Day, Belgium

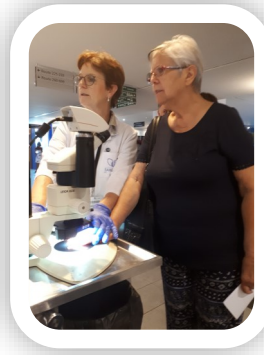
(French speaking)



This year, for the tenth year of WSD, our organisation was present in the hall of eight hospitals: two in Liège, three in Bruxelles, two in Namur and one in Tournai. Where possible, we demonstrated capillaroscopy and we provided information stands and played the WSD video where we could.

WSD lasts for one week for us because we were present on the different days the rheumatology clinics took place. Our task was to distribute leaflets and magazines about scleroderma and to explain about the disease. We began at 10 am and the hall in the hospital seemed like a human highway with people awaiting a consultation. It was an informative day and very emotional.

We were tired but it was so rewarding. We hope to be present in more hospitals in the future.



## WSD, Cyprus



ΑΝΤΙΡΕΥΜΑΤΙΚΟΣ ΣΥΝΔΕΣΜΟΣ ΚΥΠΡΟΥ  
CYPRUS LEAGUE AGAINST RHEUMATISM

*For a better quality of life*



In Cyprus we celebrated WSD19 for the 10<sup>th</sup> year in a row since it was established back in 2009.

We organized a scientific meeting for scleroderma in Nicosia General Hospital on 27<sup>th</sup> of June. It was arranged by the Rheumatology Department of the hospital together with Cyprus League Against Rheumatism. The audience consisted of patients, their families and generalist doctors.

The meeting started with the presentation of the film produced by Fesca for WSD.

A patient talked about her personal experience with scleroderma and how she copes with everyday challenges caused by the disease.

Also a pneumonologist talked about the investigation and treatment of PAH, and a gastroenterologist about how the GI tract is affected by scleroderma.

Two rheumatologists described the Raynaud's phenomenon and updates on the latest treatments for scleroderma.

The meeting was successful according to the positive feedback we received from the patients. They expressed strong wishes to have more meetings like this in the future.



# World Scleroderma Day, Italy

Once again, the World Scleroderma Day brought together the four Scleroderma Patient Organizations members of FESCA: AILS, APMAR, ASSMaF and GILS who designed two events with the support of the World Scleroderma Foundation.

The first day (June 27th) was meant mainly for patients and took place in the Library of the Italian Parliament. The location was chosen because part of the Institutions: we wanted our politicians and policy makers to know about systemic sclerosis, its complications and patients' unmet needs.

In a peculiar scenario we broadcast the beautiful video made for the campaign and the idea behind it was explained by Serena Mingolla. Her presentation was very much appreciated: the freshness, the colors and the positive message!

Prof. Marco Matucci Cerinic and prof. Elena Croci gave a particular lecture on how diseases can take a hidden but artistic element out of us. Coping with some important relevant diseases often leads to resilience processes which develop unique skills that otherwise would remain hidden. Some examples have been shown: Paul Klee, of course, who died because of scleroderma, Ludwig van Beethoven, Frida Kahlo, Henri de Toulouse Lautrec and many others. Patients really appreciated this speech, as they went over the disease and found a new way to approach their problems and find something positive in such great suffering.

Some Members of the Parliament brought their views and they promised to take actions to help us gain more awareness and rights for patients. We underlined the importance of having a special budget for rare diseases and pushed them to work in order to achieve this goal for us and with us.

We closed the day talking about ERN ReCONNET with the Network Coordinator, prof. Marta Mosca, the Italian representative in the Board of Member States, dr. Domenica Taruscio and Ilaria Galetti, the Scleroderma patients' representative in ERN ReCONNET.

Patients, clinicians and politicians appreciated the initiative and it was a pleasure to see them sharing comments and proposals.

The day after (June 28th), Ilaria spoke as FESCA

representative during a scientific Congress organized by the World Scleroderma Foundation on the heart involvement in systemic sclerosis. Rheumatologists, Immunologists and Cardiologists focused the attention only on the heart involvement of the disease, giving each of them their own expertise. Ilaria was asked to talk of the impact of heart involvement on QoL in systemic sclerosis patients and also due to the fact that the moderator was prof Khanna, who is a "patient-friendly" doctor, everything went really well.

Other activities (such as free visits, capillaroscopies, etc) took place all over Italy, proving that together we are stronger! Of course the WSD campaign was developed and spammed via several media (socials, television, magazines and newspapers). The four POs cooperated jointly and individually, reaching their audience and getting positive interactions and feedbacks. We give a positive evaluation, both for the exciting and fruitful collaboration and for the results! Looking forward to starting WSD 2020!



# World Scleroderma Day, Germany

This year we wanted to spread our message to an even wider range of people that we could not reach with our social media channels or our events. That's why we placed train posters in public transport of 4 major cities in Germany: **Berlin, Frankfurt, Munich and Nürnberg**

So the whole month of June we raised awareness of passengers sitting or standing next to the posters and reading the text while traveling. Our partner was the advertisement company Ströer Deutsche Städte Medien where we could realize our plan even with our limited budget.

On June 24, the regional group Mainz presented the 10th World Scleroderma Day during the Autoimmun Consulting in the Dermatology Clinic of University Clinic Mainz. Dr. Joanna Wegner, functional medical officer of the station, explained the extensive area of responsibility.

Our flyers have been distributed. Unfortunately due to the heat there were not as many participants as expected.

Of course we used our proven channels like posters in pharmacies and digital media like our website and the German Scleroderma Forum to raise awareness and ask for support in the German patient and supporter community.

Overall we had very useful experiences that will enable us to become even more efficient in the upcoming campaigns over the next couple of years.





# World Scleroderma Day, Sweden

## Reumatiker förbundet

Riksföreningen för Systemisk  
Skleros, SWEDEN

Botox and diets were two of the topics on the agenda at the conference on the 15th of June. That's the day the Swedish association for scleroderma patients arranged this year's WSD get-together. Around 70 people attended the event at the conference hall in Solna, just north of the capital city of Stockholm.

### Botox

Most people may associate Botox with attempts to reduce wrinkles - but Izabela Bartosik, doctor and scleroderma specialist from Lund, told us about how she helps patients with Raynaud's by injecting Botox in the palm of their hands.

Yes, it hurts, but the treatment is quick and lasts for several months. Some people with severe problems with Raynaud's may not be able to take medicine or have low blood pressure, in which case Botox treatment may be a good alternative.

### High-level entertainment

A real treat was the aria from La Boheme: *They call me Mimi*, wonderfully sung by one of our members and opera singer, Erika G. Moldenhauer. It was a tribute to us all who live and fight with our scleroderma. She also sang Summertime by Gershwin. The time of year we always long for in cold Sweden...

### Stomach, bowel, diets and research

MD Kristofer Andreasson is one of our very dedicated researchers and this lecture was wished for by our members. Problems with stomach and bowels are of course common amongst us. He also presented the latest research done nationally and internationally.

We handed out the *Scleroderma will not take my smile* brochures for our members to deliver to clinics around the country.

Thanks to all members and lecturers that made the day so inspiring!



*The Board of Riksföreningen för systemisk skleros  
Eva Milger, vice chairman, Astrid Von Rosen, Monica  
Holmner, chairman and Ewa Tingmalm, secretary. Missing:  
Gabriella Hallingström, cashier and Heleen Lever.*





# World Scleroderma Day, Denmark

In Denmark we celebrated WSD19 using Fesca material and a seminar to raise awareness on Scleroderma and celebrated in the following ways:

Advertisements based on the poster and flyer from Fesca in the health magazine „Helse“ and an advertisement in the health magazine „Sundhed“ and an article on Scleroderma in the November issue. A video from Fesca shared through our website and Facebook page, this year with Danish subtitles. Posts on Facebook about WSD19 several times.

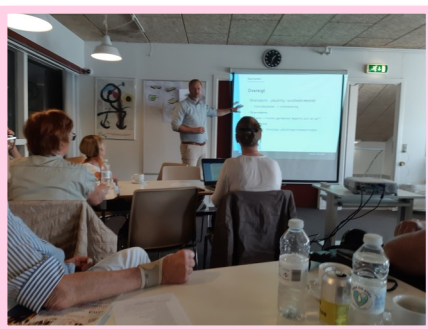
A launch seminar with thirty-four participants and two lecturers: Chairman of the committee for the local health service, Trine Birk Andersen, presented the plans for Regional Sealand. The strategy included e.g. a coherent health care system with the needs of citizens at the centre, a close and specialized health service for all and competent employees and a good working environment. The vision is more security and proximity, higher accessibility and shorter distances. Next was Christoffer Tandrup Nielsen, PhD, clinical lecturer, responsible for education, and working in the department for highly specialized rheumatology at Rigshospitalet. Christoffer presented the purpose of the specialized plan: it provides special functions and placement in hospitals, special instructions for every department e.g. rheumatology, to ensure high professional quality in the treatment and overall patient care and promote necessary construction and maintenance of the treatment.

Posters and flyers brought out to patient wards at hospitals all over the country, brought by launch seminar participants. A roll-up used at the seminar, and at our general assembly in October and posters/flyers used for advertisements and an article.

Our WSD campaign gained more momentum at SoMe, and we hope it will have some effect that a journalist wrote an article about WSD and the topics at the seminar. It also helped that we started planning early.

Among the challenges are difficulties in outreach to all diagnosed patients, and broaden the membership basis, as well as managing to assemble more of our membership to our big annual events – this mainly has to do with travel difficulties and travel expenses.

We are looking forward to next year's campaign, and hope that we can have the basic material from Fesca as early as this year. We were happy about the possibility to subtitle the video in Danish. We are grateful for the opportunity to work with and use Fesca material on WSD19.





# World Scleroderma Day, Spain

## *Do not face scleroderma alone*

Living up to the challenge so that no-one who is ill suffers alone, every year the **Spanish Scleroderma Association** extends the World Scleroderma Day activities across the country.

This year, the main event was on 29 June in **Barcelona**. The incredible modernist building **Hospital de la Santa Creu i Sant Pau** by Domènech i Montaner was our principal setting. More than 100 people attended the conference. We could listen to medical experts talking about interesting aspects of scleroderma. Among the speakers there were internists, specialists in rheumatology, in epidemiology and preventive medicine and a psychologist. At the end of the meeting, we had an informal meal together. The following day was a day of pleasant fellowship and sightseeing all over Barcelona. Evidently we visited to the **Sagrada Família**. How much beauty!

Just as the other FESCA members, we celebrated the World Scleroderma Day throughout June. The first of June we organised a meeting at the Fundación Caja Inmaculada in **Huesca**. Qualified specialists from Hospital San Jorge talked about scleroderma issues like the importance of early diagnosis, or chronic wounds.

The second meeting was on 15 June, in **Antequera (Málaga)**. There we managed to bring together 52 participants at Hospital Comarcal de Antequera. We were fortunate to have a Professor of immunology at the Córdoba University as a lecturer. On 22 June, the Spanish Scleroderma Association ran a meeting at **Hospital Universitario Gregorio Marañón in Madrid**. The speakers were a rheumatology, a psychologist and a patient who shared her own experiences in facing scleroderma. We have to thank FESCA for the materials it provided (video, roll ups) that we brought to all these meetings.

But not everything was academic knowledge as we also scheduled leisure activities. **Teatro Flamenco de Madrid** organized an exclusive show for us. On 23 June “Emociones a flor de piel” interpreted by flamenco dancers and singers was really amazing. And we were lucky to count with a famous basketball player as presenter.

As complementary activities, we installed **information stands** in **Las Rozas (Madrid)** on 18 June and in **Cornellà de Llobregat (Barcelona)** on 23 June. Although it may seem an outdated way of bringing visibility, it is very important to give people information in person. And of course we could not miss our “**Cafes de Amigos de Sclerodermia**” - Scleroderma Friends cafe- sign of identity of the association. On June we convened partners in Palma de Mallorca on 1 June, in Gerona on 9 June, in Bilbao on 18 June and in Barcelona on 25 June.

As the reader can imagine we ended up exhausted with so much activity. But we are already recovered and looking forward to reaching more people next Scleroderma World Day.



Scleroderma Friends Café, "Café Amigos de Esclerodermia" - Bilbao

# World Scleroderma Day, UK



Scleroderma & Raynaud's UK supported the 'Scleroderma will not take my smile: a whole world of support' campaign for World Scleroderma Day 2019, using the #sclerosmile across our social media platforms, both on the day and during the month of June. We shared the campaign imagery on our Social cover photos, which was seen by more than 2,700 people and across several Tweets/Posts achieving more than 11,000 impressions.

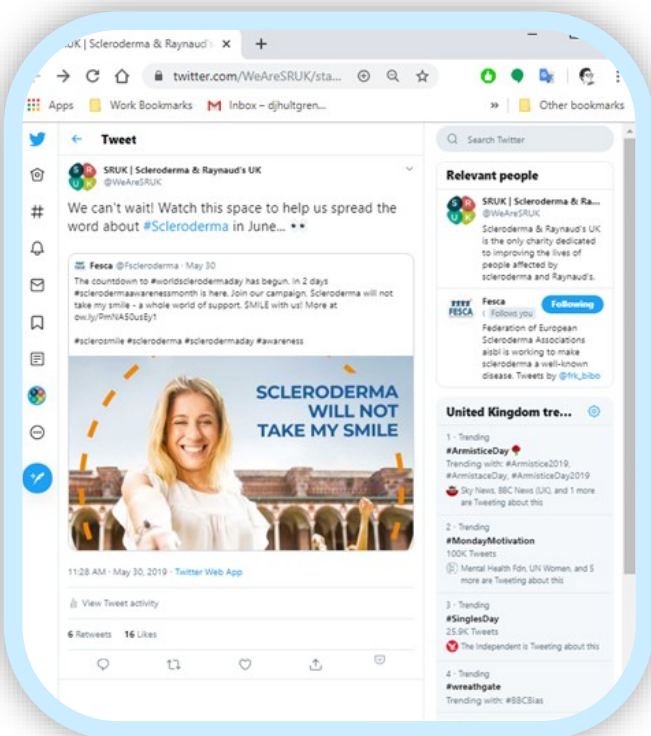
We developed a full media campaign, targeting TV, Radio and print to increase awareness of Scleroderma - the signs and symptoms.

We distributed a FESCA themed press release ahead of World Scleroderma Day. In the lead up to SAM and during the month, we secured 18 pieces of print, digital and TV media coverage and 23 pieces of radio press.

We did live interviews with 25 radio stations, featuring a representative from SRUK and someone with scleroderma who shared her own very powerful story. We reached an audience of 8,278,000 listeners with coverage all over the UK.

We asked our community to help us spread the word by downloading the FESCA poster from our website, watching the embedded YouTube video and joining in the conversation using the #ScleroSmile hashtag. To highlight the impact that scleroderma can have, we also prompted our community to send us their #TenYearChallenge photos, showing how they had changed over the past decade. We featured these across our Social Media on World Scleroderma Day, which elicited many others to take part. We also published 4 videos throughout the month asking them about their experiences of being diagnosed, their first symptoms and what one thing they would like everyone to know about scleroderma.

Our community told us that explaining their condition to family and friends was a challenge and so through the support of FESCA we were able to produce an animation to help our community share with friends and family. The animation was viewed for 25,300 minutes in total, reaching over 100,000 people and helping them get to know scleroderma.





# World Scleroderma Day, Croatia



*HRVATSKA UDRUGA OBOLJELIH OD SKLERODERMIJE (HUOS)*

*CROATIAN ASSOCIATION FOR PATIENTS WITH SCLERODERMA (CSPS)*

**„Sklerodermija mi neće oduzeti osmijeh!“**

To celebrate and raise awareness about Scleroderma, HUOS/CSPS organized a day in the Zagreb City Zoo on World Scleroderma Day for its association members and volunteers including several physiotherapists and the president of the Zagreb City Hall, Prgomet Drago and his secretary.

The day was filled with interesting presentations and facts about the animals we were seeing but most importantly about the turtles since a turtle is a part of our association symbol which the children particularly enjoyed because they were able to touch, interact with and learn more about them.

The association President, Jadranka Brozd, gave a speech where she thanked everyone for coming to celebrate WSD19 and finally presented the book named “Happy Little Armours” about a turtle named Valeria, written by Silvija Šesto and illustrated by Boris Kugler. After the presentation and the promotion of the book, everyone was invited to have lunch in a restaurant inside the zoo. The lunch was filled with fun, laughter, great advice and amazing food.

Jadranka Brozd and a few of the association members also had several media appearances throughout the year where they talked about Scleroderma, life with Scleroderma and World Scleroderma Day trying to raise awareness and get more people involved.

The meetings and workshops were also attended by Jadranka Brozd and association volunteers Sanja Roškar and Matea Perković Popović.

**We hope to be even better next year!**

*World Scleroderma Day in Zagreb Zoo:*



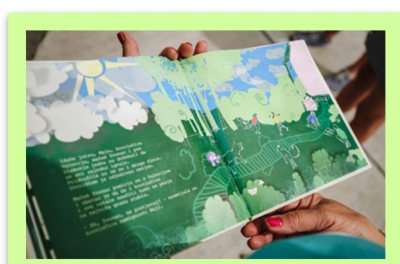
*Z1 TV – TV Show „Good Morning, Zagreb“*



*Interview for „Dobro Jutro, Hrvatska“ (Good Morning, Croatia) with the association president Jadranka Brozd.*



*The cover of the book „Happy Little Armours“.*



*Apple TV – TV Show „The Everyday Life“.*



# World Scleroderma Day, Portugal

Associação Portuguesa de Doentes com Esclerodermia (APDE)

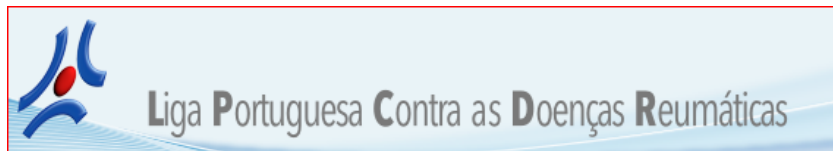


This year, to commemorate Scleroderma Day, we organized a meeting of patients. In this meeting we developed a game, "The Scleroderma Game". Thus, the patients divided into teams and tried to answer the questions that were organized by category.

There were several doctors present who were giving explanations on each of the questions. The winners got t-shirts alluding to the day of scleroderma. After a lunch together with patients, doctors and families, we had a moment of sharing testimonials. Several patients shared their stories, it was very emotional but also very positive.



# WSD, Portugal



## Portuguese League Against Rheumatic Diseases (Liga Portuguesa contra as Doenças Reumáticas)

Several activities were carried out by the Scleroderma Patient Group of Portuguese League Against Rheumatic Diseases this year!

We organised a Spinning® Event as a way of raising awareness and spreading the word about scleroderma, which was a success. It was six hours of an Indoor Cycling Marathon with 70 bicycles, in which we gathered around 300 people. Some of them had never heard the word scleroderma before and it was a different way to learn a little about the disease.

Several patients also cycled and it was possible to socialize with the rest of the participants. Physical exercise can be part of the life of a scleroderma patient, as long as it is done properly, and that is what we also wanted to show.

The amount raised will also help the patients with the expenses they will have from participation at the world congress. At the end we had some cupcakes with Spinning® and scleroderma symbols that made the delights of the participants!

On World Scleroderma Day we attended a Congress for Scleroderma patients which helped to clarify doubts that everyone has in their daily lives. As usual, every year we organise a patients' lunch, which is always a very pleasant time that helps the patients and their families to live better with the disease.

We used FESCA material in several pharmacies that promptly joined the campaign, as well as Hospitals and Health Centres. We are really very happy with the activities we organized and with the result we achieved this year!





## What is scleroderma?

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

## How many people have scleroderma?

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

## Member Organisations:

### Belgium

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

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

### Croatia

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

### Cyprus

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

### Denmark

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

### Finland

Finnish Scleroderma Association  
<http://244846.edicypages.com>  
[marjo70.makela@gmail.com](mailto:marjo70.makela@gmail.com)

### France

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

### Germany

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

Scleroderma Liga e.V.  
[www.scleroliga.de](http://www.scleroliga.de)  
[reeb.maria@t-online.de](mailto:reeb.maria@t-online.de)

### Hungary

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

### Ireland

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

### Italy

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

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

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

Associazione Persone con Malattie Reumatiche  
<http://www.apmar.it>  
[info@apmar.it](mailto:info@apmar.it)

### Norway

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

### Poland

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

## Federation of European Scleroderma Associations (FESCA )

### International Non-Profit Association Registration No: FOJ 15454

Email: [info@fesca-scleroderma.eu](mailto:info@fesca-scleroderma.eu)

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

### Registered address:

FESCA aisbl  
Rue du Pont à Rieu 13 i  
7500 SAINT MAUR  
BELGIUM

**President:** Annelise Rønnow, Denmark

**Vice-President:** Alexandra Portales, Spain

**Secretary:** Linda Schraven, The Netherlands

**Treasurer:** Gabi Niehaus, Germany

### Counsellors:

Kim Fligelstone, U.K.

Ilaria Galetti, Italy

Beata Garay-Toth, Hungary

Ann Tyrell Kennedy, Ireland

Joep Welling, Netherlands

Despo Charalambous Demetriou, Cyprus

### Portugal

Portuguese Association of Patients  
with Scleroderma  
[associacao.apde@gmail.com](mailto:associacao.apde@gmail.com)  
[info@esclerodermia.pt](mailto:info@esclerodermia.pt)  
[www.esclerodermia.pt](http://www.esclerodermia.pt)

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

### Romania

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

### Spain

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

### Sweden

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

### Switzerland

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

### The Netherlands

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

### U.K.

SRUK (Scleroderma & Raynaud's UK)  
[www.sruk.co.uk](http://www.sruk.co.uk)  
[info@sruk.co.uk](mailto:info@sruk.co.uk)