

Welcome from our President

A Year in Review

Welcome to yet another edition of FESCA's newsletter. 2018 has been a year with lot of activities in FESCA starting with the Systemic Sclerosis World Congress in Bordeaux this February. Thank you to the French Association for doing all the logistic details on a local basis. It would not be done without you! Also a big thank you to Yanne who was the World Congress Manager. Unfortunately Yanne was sent to hospital with a very bad ulcer and missed the World Congress – I and the rest of the team missed you too! Next World Congress is in Prague 2020. If you have any suggestions for content, please send to the board. We are open for good ideas.

The activities in FESCA this year have been very hectic. Almost the entire board has traveled round the world to meetings not only in Europe but also outside Europe. E.g. Joep participated in the Canadian conference, and we are very proud of Joep as he won an award – the very first one introduced by SPIN. Read all about it in this newsletter. Ilaria is all over Europe working hard with ERN ReCONNECT and making sure that scleroderma is visible on the map. Annie is representing FESCA at conferences and meetings, and even though we are still in 2018, our calendars for next year are getting booked already.



In February, I am presenting FESCA at the EUSTAR course in Nijmegen.

World Scleroderma Day 2018 (WSD18) was again a successful event. This is the second time we used the slogan, “Scleroderma Will Not Take My Smile”, and we have seen that not only members of FESCA have used #sclerosmile, but we have seen on social media that #sclerosmile was used all over the world, like China, Brazil, Turkey, Mexico, USA & Canada just to mention a few. I am also sending out a big congratulation to the Canadian association, and Scleroderma Foundation & Scleroderma Research Foundation for lighting up the Niagra Falls on World Scleroderma Day.

WSD18 was introduced at EULAR in Amsterdam at our stand. We had the poster in all the translated languages on display in the stand and rheumatologists from all over the world dropped by to talk. We even showed the video on our computers to those who were interested.

We are already in full speed for next WSD. Again we will use “Scleroderma Will Not Take My Smile”. This

time we are teaming up with lovely Serena Mingolla to be the Project Manager. Serena is an Italian Communication Manager and journalist since 2003. She is Director of the Italian magazine “Morfologie”, a publication aimed at patients circulating scientific information in a simple and creative way, edited by AP-MAR, Italian National Association of Persons with Rheumatic and Rare Diseases. Serena and the World Scleroderma Day manager of 2018 are working very closely to develop the concept of WSD2019 with “Scleroderma Will Not Take My Smile”.

Within a few weeks our members will receive the first messages and translation of the posters will begin at the end of January.

I look forward to our continuing work, collaboration, meetings, conferences, and much more.

Scleroderma Will Not Take My Smile!

Happy New Year!



*Annelise Rønnow,
President,
Federation of European
Scleroderma Associations
aisbl.*

Scleroderma Framed

Scleroderma Framed is a Dutch organization founded by **Jessica Thonen-Velthuisen** more than 10 years ago. Having scleroderma herself, Jessica knows how the disease can affect the body and mind.

With Scleroderma Framed, Jessica is focusing on scleroderma in a very artistic way. With the professional photographer Hans Peter van Velthoven, she has made a photo-book, which they have toured with for many years. The concept is to show the beauty of a person with

scleroderma – by having a professional make-up artist to do the make-up and hair and a photographer to take pictures.

This year, the book came out as a 10-year anniversary edition, and two people from the FESCA board are amongst the first people outside the Netherlands to participate.

For more information, visit www.sclerodermaframed.com.

Scleroderma
Framed

10 year anniversary

Caddy Delhove-Droulez: Rest In Peace

We listened to Caddy when she gave us advice, when we wanted to create FESCA. She said that it was difficult, but that there was a way. We just had to persist.

At the very beginning of FESCA, Caddy was the one with the most experience, the most wisdom. We were seven national patient scleroderma associations that were gathered together in the hopes of creating an umbrella organization for Europe, and Caddy was president and founder of one of them, in Belgium.

The UK and Germany had older associations, but that meant that they had not recently dealt with the struggles of developing a Constitution, a Strategic Plan, a financial support system--that had all been done 25 years prior. But Caddy had done that recently. As Kim said, she was like the mother of FESCA, and we turned to her for assurance that we could do it, even though she was not going to be the one doing it all, since she already had to run her association in Belgium.

Caddy left us forever this summer. It surprised us all, because none of us realized how ill she was. She was still full of smiles and encouragement when last we saw her. We will miss her enormously. Her husband Jean had come to early AGMs, and took photos, so we got to know him too; and she showed us the pictures of her children and of her grandchildren. Our hearts go out to all of them, as we mourn with them.

To all of them, from all of us at FESCA, we send our warmest wishes, and our sincere condolences.



Scleroderma Congress, Calgary, Canada

Joep Welling and Linda Kwakkenbos attended and presented at the Scleroderma Congress in Calgary, Canada on 22-23 September 2018 .

There was an interesting and diverse program: exercising to raise more awareness for scleroderma, and experts who shared their experiences and other information.

Dr. Matucci-Cerinic provided his keynote lecture through videoconference and there were several other speakers on a variety of topics.

On Saturday, SPIN-SHARE (SPIN - The Scleroderma

Patient-centered Intervention Network) was launched: SPIN's framework to make tools available free-of-charge, to help people live better with the disease, such as a structured hand exercises program.

During this session, Joep was honoured with the inaugural Maureen Sauvé Inspiration Award for his efforts.

Dr. Wigley, rheumatologist at Hopkin University USA concluded the congress with a patient-oriented lecture.



Photo left-right:

Dr. Brett Thombs, Director, Scleroderma Patient-centered Intervention Network (SPIN)

Joep Welling, FESCA Board Advisor

Linda Kwakkenbos, Co- Director, Scleroderma Patient-centered Intervention Network (SPIN)

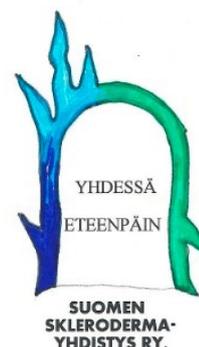
World Scleroderma Day, Switzerland

This year we made a flyer and poster and we sent it to hospitals. We also made a greetings card (see right) so throughout the year when we send out a package, we include this card.



World Scleroderma Day, Finland

For WSD, we translated videos from the scleroderma congress. We made magazines of those, and lot of other things. We then printed the magazines and sent those to our members.



Scleroderma Framed



Book presentation "10 years Scleroderma Framed, 100 + 1 models"

In order from left to right:

Prof. dr. Frank van den Hoogen (Advisor)

Sharon Persijn & Lobke Tissen (both volunteer)

Jessica Thonen-Velthuisen (Founder & President of Scleroderma Framed)

10 years of Scleroderma Framed: 101 scleroderma models in new book to celebrate anniversary.

On World Arthritis Day, October 12, there was a fantastic party in Nijmegen, the Netherlands. The Scleroderma Framed Foundation celebrated their ten-year anniversary of 'Scleroderma in the spotlight', a series of photos in which the foundation portrays people with scleroderma in a positive way. A new book, in which all 101 models with scleroderma are portrayed, is the culmination of this anniversary.

The idea for 'Scleroderma Framed' arose ten years ago when the founder of the Scleroderma Framed foundation, Jessica Thonen-Velthuisen, ended up in hospital with scleroderma. She had to undergo a stem cell transplant in 2006 for this rare, disabling and sometimes life-threatening connective tissue disorder.

Jessica: "My dream was to raise awareness for this unknown disease in a positive and artistic way." Jessica approached the well-known photographer Hans Peter Velthoven. He was enthusiastic about the project right away, and immediately started working with Jessica.

Focus on the person, not the disease

Photographer Hans Peter has a unique and personal way of working, with which he tries to get very close to the heart of the models. This requires the models to be vulnerable in his presence. With the photographs, the attention is shifted from the typical appearance of the disease scleroderma to the person behind

the disorder. Prof. dr. Frank van den Hoogen has also been connected to the project from the start: "I will never forget the moment when the photos were shown to the models, their partners and family members for the first time. That was a really emotional moment. Everyone was amazed at the beauty of the photo. Unbelievable that you as a person can be portrayed so beautifully."

(inter)National Successes

Ten years later, and with 101 portraits being made, Scleroderma Framed Foundation consists of Jessica as well as a team of 19 volunteers who help her to realize her dream of getting scleroderma 'in the spotlight'. Slowly but surely the Scleroderma Framed Foundation is gaining even more traction, both nationally and internationally. Over the past ten years, the foundation has participated in international conferences, exhibited in a large number of Dutch and foreign hospitals and exhibited at the Ministry of Health, Welfare and Sport in the Netherlands and in the EU in Brussels.

Positive experiences

Back to the book presentation on October 12 in Nijmegen. Jessica, Frank, Hans Peter, and model and volunteer (both for Scleroderma Framed and the Dutch Patient organization NVLE) Sharon Persijn, shared their experiences and motivation for their involvement in Scleroderma Framed.

During this special afternoon, the models, their partners, family members or friends also have the opportunity to share their experi-

ences. Although the photos sometimes led to an initial confrontation with the appearance-related changes that scleroderma brought to a person, everyone is ultimately very happy with the result and the shoot has had a positive effect on the participants. This is endorsed by researcher Linda Kwakkenbos, who investigates the psychological effects of having scleroderma. People with scleroderma often experience, as a consequence of their changes in appearance, a less positive self-image. During the book presentation, Frank van den Hoogen indicated that research has shown that the photo shoots have a positive effect on the self-image of the models.

Unveiling the cover

The first two models from ten years ago, Laura Hinssen and Linda Schraven had the honor of unveiling the cover of the new book together with Jessica. Volunteer Lobke Tissen then received the first copy of the book on behalf of all volunteers.

After receiving three large donations from the audience, Jessica thanked everyone who is so passionate and dedicated to Scleroderma Framed, the volunteers, the models, partners, family and friends. Without them, Scleroderma Framed would not exist. Jessica: "We all work with the same goal in mind: more awareness for scleroderma!"

By: Talitha Dhondai
Linda Kwakkenbos & Jessica Thonen-Velthuisen

World Scleroderma Day, Germany

„Sklerodermie wird mir mein Lächeln nicht nehmen - weltweite Unterstützung“

This slogan travelled around Germany for the second year running, enabling us to support more than 10,000 people with scleroderma including our about 1,000 members of the Sklerodermie Selbsthilfe e.V.

With the focus on creating awareness among the general public, health stakeholders, doctors, pharmacists and patients as well as informing people about the disease of systemic sclerosis, several events were carried out by the board and regional groups all over the country.

As previous years, we sent posters to all the clinics of the DNSS (German Network for Systemic Sclerosis).

In the eastern and southern parts, the regional groups Munich, Augsburg and Leipzig distributed handouts at local events within their community. Additionally, the regional group Munich was happy to have an information stand for two days in the lobby of the museum, "Pinakothek der Moderne" during the Paul Klee exhibition, "Konstruktion des Geheimnisses".

In the very north, a patient day was organized at the University

Clinic of Lübeck (UKSH) by Prof. Dr. med. Gabriela Riemekasten and her team on 29th June 2018. This event was aimed at patients and other interested parties who wanted to find out about the current state of therapeutic options and to exchange ideas with others around the topics of fatigue, nutrition in collagen and rheumatic diseases, exercises as well as new research projects at the clinic.

Finally, the highlight of the WSD was a press conference with the DNSS in July 2018 with the main topics of early diagnosis of pulmonary involvement in SSc and early treatment of PAH in SSc. It served the purpose of "training" doctors and the "awareness" of pulmonary involvement and the earliest possible treatment. The lessons of the press conference were published in eight different specialist magazines with a total circulation of 83,995 copies.

We thank the members of FES-CA for their tireless dedication and support.

Gabriele Niehaus,
Sklerodermie Selbsthilfe e.V.
Regionalgruppe München



World Scleroderma Day, Hungary



As our slogan this year says “Scleroderma will not take my smile!”, a whole world of support for our campaign in Hungary really happened this way! As every second year we had regional programs with members of the associations, doctors and HCPs. We organized outdoor activities in three main cities which all host medical universities and rheumatology clinics, too. It was the cities of Pécs, Szeged and Budapest with different outside programs. Our campaign is integrated each year - in 2018 we also used different channels for raising awareness for World Scleroderma Day.

Beside the regional outdoor programs, we had two PR articles, social media usage (Facebook, Twitter and Instagram – banners, #sclerosmile, info, etc.), our own website and we also placed leaflets and posters on the walls in the main scleroderma/rheumatology/dermatology centres, ambulance and hospital departments. The new video film was very much liked on our social media network and also among our members.

The two PR articles appeared in the most read daily paper and the other in the most read women’s magazine. Three of our SSc patients of different ages and condition were interviewed (they were in their 20s, 30s and 40s respectively) and told their stories of how they can cope with this disease with a whole world of support and also how they have smiles during their fights. The articles contained the creative elements of the campaign and the slogan and a short introduction about FESCA and our association.



PR articles

During the regional outdoor activities, the members, carers, doctors and HCPs who participated raised awareness during the walks and excursions downtown.

The Pécs team used Dotto, a little sightseeing train to go around the city and arrived in the main museum quarter Zsolnay where they distributed leaflets and displayed posters. Our President Emese Molnar led the team and answered questions. Physiotherapists and nurses also joined them during a pleasant lunch.



PÉCS

The Szeged team used the local city boat on the River Tisza after walking through the city with awareness raising posters on the boat, distributing leaflets. After the awareness raising activities, they went to have lunch where our President, Emese Molnar and Dr. Daniella Hullo rheumatologist gave a speech about the World Congress patient and medical sides and other activities. It was a pleasure to see that the widow, Gabriella Szabóné, of our late President, Béla Szabó joined us to continue helping us raise awareness.



SZEGED

[continued on next page]

In Budapest a longer excursion was made combined with awareness raising (posters on the boat, distributing leaflets), through the Danube up to a lovely city close by, Szentendre, which is a tourist enter. A nice lunch was taken with talks and questions among the members.



BUDAPEST

All in all we can say this year was also a very creative and successful campaign about raising with a whole world of support and big smile.

Beata Garay Toth



ΑΝΤΙΡΕΥΜΑΤΙΚΟΣ ΣΥΝΔΕΣΜΟΣ ΚΥΠΡΟΥ
CYPRUS LEAGUE AGAINST RHEUMATISM

For a better quality of life

WSD, Cyprus

We had a scientific meeting in collaboration with the Medical School of the University of Cyprus and the General Hospital on the 28th of June. A rheumatologist, cardiologist and pulmonologist talked about scleroderma symptoms and treatment as well as about the importance of early diagnosis. Also Despo Ch.Demetriou (a person with scleroderma) talked about her everyday experiences and difficulties with scleroderma. The meeting was under the auspices of the Ministry of Health. There were about 40-50 people who were interested and attended the event. At the meeting there were doctors, health professionals, medical students and patients.

Also in Cyprus we ran a social media campaign. The film for WSD18 prepared by FESCA was shown during the month of June. A special profile frame on Facebook was used by our members with the slogan, "Scleroderma will not take my smile". It was a great success and it was copied by other people affected by scleroderma all over the world. A personal story of a girl with scleroderma received more than 10,000 likes on Facebook. Journalists were interested in it and mentioned it on TV and this had a positive result for awareness.

Members of the Cyprus Association were invited to create a closed group for scleroderma patients. As a conclusion, I believe that overall awareness had a better impact on the public. People with scleroderma have begun to speak about scleroderma more openly. Year by year awareness is growing.

World Scleroderma Day, Belgium

[French speaking]

Just like last year, our members were present in eight hospitals. WSD was on June 29th but in order to be present in hospitals on the days the rheumatology clinics were held, we had to change our attendance to another day of the week.

We had information stands, information from rheumatologists present on the day and in some hospitals, the opportunity for people to have a capillaroscopy.

We were welcomed in the majority of hospitals.

So now we are ready for 2019!



Association des Patients
Sclérodermiques de Belgique



WSD Italy (AILS)



AILS, in collaboration with the CReI- Collegio Reumatologi Italiani, proposes a particularly interesting initiative, a photographic exhibition to celebrate the X World Day of Scleroderma, entitled “Diseases without Dignity”.

The exhibition, in its complete form, consists of 50 commented panels, showing an ideal emotional journey of patients, sometimes made of suffering, misunderstanding and lack of recognition.

This is a new event that allows us to talk about diseases such as scleroderma/systemic sclerosis for which early diagnosis plays a fundamental role in avoiding significant disability and saving lives; to ensure that they do not remain unknown, that they are not underestimated, and that they do not lose dignity.

AILS, together with other sector associations Ap-mar, Assmaf, Gils, has also organized, in various hospitals throughout Italy, awareness events in support of early diagnosis, providing the opportunity to have video-capillaroscopy and medical assistance with free access.



World Scleroderma Day, Germany



Scleroderma Liga e.V.

Since this was our first year as a member of FESCA and thus our first WSD campaign, we had much to learn. So for next year will be much better prepared, but this year we did our best.

We expected to start at our annual therapy conference in April, but the material was not ready by then. So we used it at all the other events between June and August 2018 where we presented our group to patients, their families and friends, but also to the public to raise awareness and get support.

One of these events was the “Selbstival“ in Nuremberg on June 30. The name is a combination of “Support (group)“ and “festival“ and this name is the program: It’s a market where patient organizations can present themselves and their goals together with a free & outdoor festival where great bands perform on stage and play music that people like to hear and dance to, poetry slam and comedy, and of course delicious snacks and beverages. This offers the opportunity to raise awareness among a wide range of people.

We presented the WSD material together with our material from our own association to raise awareness for scleroderma in a very well frequented event. So it was a success.

We attended several other similar events e.g. in Mainz and Bad Nauheim. Additionally we distributed the posters and flyers in hospitals, medical practices and pharmacies all over the country where we have groups.

Of course, we put the material together with the great video on our website. The high quality of the material all together was a great benefit to all of our activities. A big thank you to the FESCA WSD team 2018.

For next year we are planning a special event for WSD. We’ve taken the first steps already.



*Our stand at the Selbstival on June 30, 2018.
Location: Jakobsplatz in Nuremberg*

World Scleroderma Day, France



For World Scleroderma Day in France, the ASF regional delegates arranged more than 14 events in different cities. A web conference was organized on June 22nd with the Alliance of Rare Diseases.

Meetings between doctors, patients and their relatives were organized to discuss the different aspects of the disease such as lungs, kidney and skin. Specific therapies and their long-term effects were also discussed. Increasing awareness and knowledge of the disease hopefully will also decrease the reports of feeling isolated and frustrated due to the lack of understanding among work colleagues, acquaintances and relatives.

Quote from a participant: *“This afternoon was a success both from the point of view of sharing information and receiving support to better live with this rare and complex condition. It was a really nice atmosphere between doctors of different specialties and patients allowing us to ask all the questions that we could have.”*

Events ended with a convivial snack where again participants could easily exchange with patients and doctors.

Through the different events, we were able to reach about 800-900 people at least, both patients and their relatives. We also engaged with about 60-70 different doctors and/or scientists. We witness great commitment from the medical team year after year.

The FESCA WSD poster and the FESCA film were used in every event. All events were announced on Facebook with the WSD campaign materials. All FESCA materials were made available on the ASF website.



World Scleroderma Day, Italy (GILS)



For WSD2018, GILS organized initiatives for patients, doctors and lay people in order to raise awareness of scleroderma, early diagnosis and new treatments.

Several interviews on national TV channels, a press conference and a press dinner were organized: FESCA representatives, prof. Matucci and prof. Gallie' explained the disease and focused the attention on lung involvement, including fibrosis and PAH.

Articles in newspapers, magazines and social publications are still in run, as the aim was to cover as many months as possible.

Moreover we posted the FESCA film on social networks as well as on our website; the insights and analytics show that thousands of people saw our posts.

In Rome, together with the other Italian Associations, we organized a conference with many doctors and patients which was very interesting; Ilaria, as a member of the FESCA Board, spoke on behalf of all the associations.

In dozens of hospitals all over Italy free capillaroscopies and visits were held, achieving resounding success. Several early diagnoses were made.

We are happy with the result achieved during the WSMonth (the initiatives ran all over June and even longer) as we reached the determined goal: raising the awareness on the disease and spreading the #ScleroSmile message.



World Scleroderma Day, Portugal



To disseminate awareness about scleroderma and within the framework of commemorating scleroderma day, we went to the national television channel, where we had a few minutes to talk about the disease. We distributed leaflets to several hospitals in the country and we organized lectures with several doctors and we also hosted a lunch for patients and relatives with almost 200 participants. We did a little movie to spread scleroderma as well.

World Scleroderma Day, Sweden

“Scleroderma will not take my smile”

Around 40 members gathered at Hotel Scandia Klara in the City of Stockholm on the 9th of June to celebrate WSD 2018.

Professor Emeritus Frank Wollheim who started the first scleroderma clinic in Sweden in 1974, gave a lecture on “Disappointment, Success and Hopes for the Future Regarding Treatments of Scleroderma.

After a lovely Swedish “fika” (coffee and cake) the scleroderma specialist, Doctor Annika Nordin, answered the audience’s questions about scleroderma.

There were many questions, for example about problems with the stomach and intestines, food, ulcers and change of facial appearance. We had a great discussion in the group about how it is to live with scleroderma and how to take on the challenges when they come.

Many Swedes are already on holiday on the 29th, so we met earlier in the beautiful month of June. We handed out FESCA scleroderma awareness leaflets and encouraged all to pass them on.

On Facebook, the Swedish organization spread the campaign “Scleroderma will not take my smile” on several sites. We reached a couple of thousands views. Clinics all around Sweden put the posters up and we have received positive feedback via mail.

Monica Holmner, the head of the Swedish Association with FESCA-leaflets and information about scleroderma.

Reumatiker förbundet

Riksföreningen för Systemisk
Skleros, SWEDEN



World Scleroderma Day, Denmark



In Denmark we celebrated WSD18 in the following ways, using FESCA material and a seminar to raise awareness on scleroderma:

Advertisements based on the poster and flyer from FESCA in the health magazine "Helse" and presenting flyers at their information booth at "The People's Political Festival" in Bornholm.

An advertisement in health magazine "Sundhed" and an article on scleroderma in the June issue.

A video from FESCA shared through our website and Facebook page.

A launch seminar with 46 participants and two lecturers: Reumatologist John Bonde Knudsen on systemic sclerosis, diagnosis and treatment today; and Nanna Marinussen, patient since childhood and blogger, on her life with scleroderma. From the seminar we sent an open letter to health authorities and politicians, to health magazines and the health desk of major daily newspapers.

It has so far resulted in responses – and invitations for cooperation – from the health magazines and a major patient organisation called "Gigtforeningen"

Posters and flyers taken out to patient wards at hospitals all over the country, brought by launch seminar participants.

A roll-up used at the seminar, and transmitted through Nanna Marinussen's blog.

Flyers handed out by "Helse" on Bornholm at "The People's Political Festival" .

Posters/flyers used for advertisements and articles.

Our WSD campaign gained more momentum than previous years, due to cooperation with Boehringer-Ingelheim – made possible through the World Congress in Lisbon and Bordeaux.

It also helped that we started planning early!

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

We are grateful for the opportunity to work with and use FESCA material on WSD18.



World Scleroderma Day, Spain

Together, the Spanish Scleroderma Association and all its members put together a successful campaign for World Scleroderma Day 2018. June is the month to strengthen our efforts to be seen and heard, increasing our activities.

The result has been a strong campaign program, a mix of informative and instructive activities for those who wanted to learn more about the disease, meetings for patients and their families and friends to give them the opportunity to share their personal experiences with the disease and find the support they need, and of course awareness-spreading events.

The campaign began on social networks, which have been present and part of all the activities, centered on the 2018 slogan “Scleroderma will not take my smile - A whole world of support”. The first important event was held in Zaragoza on June 11th, at the Lozano Blesa University Hospital, where the Aragon Government Minister for Health, Sebastián Celaya Pérez, opened a session of conferences about scleroderma, including lectures and interactive sessions between doctors and patients about the main concerns of scleroderma patients. The conference session was followed by a meal, and the annual general assembly - every activity was a good occasion to network and share personal knowledge and experiences.

There were also conferences on scleroderma for people to attend in Madrid, at the HM Sanchinarro University Hospital. The lectures were given by renowned specialists and gave the opportunity to approach different topics: new treatments, clinical trials, physical exercise, and the benefits of mindfulness.

Finally, patients from the Barcelona region once again demonstrated a zest for life and full involvement with World Scleroderma Day; they organizing a full day's event for spreading in Cornellà de Llobregat, with popular outdoor activities, like a *butifarrada*: “*butifarrada*” (a gathering where people eat *butifarra*, a traditional sausage from Catalunya), live music and a Zumba masterclass.

In many cities like Valencia, Castellon, Santander and Barcelona, patients attended informative points at hospitals and central squares, as places for spreading awareness, giving information and the chance to meet patients. Others participated in radio programs to talk about scleroderma.

This summary cannot end without expressing our gratitude to all those who have supported us, making our campaign possible and contributing to its success, especially hospitals, institutional and political representatives, doctors and speakers, and all the participants and patients, who are always the soul and *raison d'être* of this campaign.



Barcelona



Madrid



Zaragoza

World Scleroderma Day, UK



Scleroderma & Raynaud's UK - World Scleroderma Day 2018

Scleroderma & Raynaud's UK supported '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 asked our community to help us spread the word by downloading a poster from our website and joining in the conversation. To highlight the importance of family, friends and carers we produced three videos highlighting different stories from our community. We featured a mother and her daughter; a husband and his wife; a son and his mother. We asked them about their experiences of being diagnosed, their symptoms and how they deal with them. A focus of the films was about their relationships, their support networks and what this means to them.

To celebrate World Scleroderma Day, Actelion invited SRUK to work with them on an innovative art project to help communicate mes-

sages around recognising symptoms, early diagnosis, day-to-day living as well as the importance of optimum management.

As World Scleroderma Day is celebrated on 29th June, the date on which renowned artist Paul Klee died from the condition, four people living with scleroderma in the UK were invited to take part in an art class to create Klee-inspired works that reflected their own emotions about living with the disease. As part of the project, each participant was filmed giving a short interview about their personal scleroderma journey.

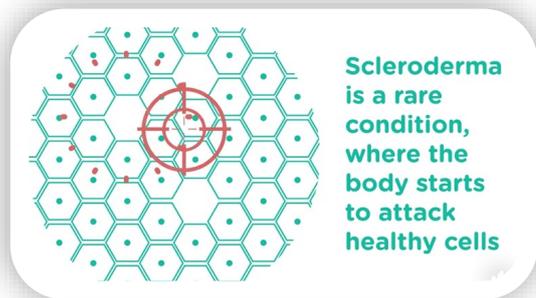
Photographs of the resulting artwork and films were then shared as part of a creative social media campaign for the day and the week following World Scleroderma Day.

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 shared over 1000 times on FB leading to the animation being viewed over 36,000 times.

'Thank you, this is an excellent learning tool and will help people understand what my husband is going through.' Diana

Alongside working with national and regional press, we had a big radio push at the beginning of June to raise awareness of the condition in the UK. We did live interviews with 25 radio stations, featuring a representative from SRUK and someone with scleroderma who shared her own very powerful story.

'What an amazing interview. I have scleroderma and I find it so hard to explain to friends and family how it affects me. This interview says it all!' Sue



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

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 Association
<http://www.sklerodermi.dk>
info@sklerodermi.dk

Finland

Finnish Scleroderma Association
<http://244846.edicypages.com>
marjo70.makela@gmail.com

France

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

Germany

Patient Organisation for Scleroderma
www.sklerodermie-sh.de
sklerodermie@t-online.de

Scleroderma Liga e.V.
www.scleroliga.de
reeb.maria@t-online.de

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

Associazione Persone con Malattie Reumatiche
<http://www.apmar.it>
info@apmar.it

Norway

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

Poland

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

Federation of European Scleroderma Associations (FESCA)

International Non-Profit Association

Registration No: FOJ 15454

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info@esclerodermia.pt
www.esclerodermia.pt

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

Romania

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

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

[sclerodermie.ch](http://www.sclerodermie.ch) (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.

SRUK (Scleroderma & Raynaud's UK)
www.sruk.co.uk
info@sruk.co.uk