

# FESCA NEWS



## Welcome from our President

December 28, 2016

My dear friends,

What a busy year we have had, starting with our world congress in Lisbon, an amazing feat for a purely volunteer federation like FESCA, and a huge success. My praise and thanks go to all who helped to organize it. Now, as 2017 begins, we have no congress to prepare, but in Feb 2018 we will hold the next world SSc congress in Bordeaux. For the first time, this will be developed not by me, but by a new manager, Dominique Godard, with Yanne Courcoux and her team. More workshops and fewer lectures is the concept, and as always, we put the patient and the patient's story first.

Our thanks also go to the manager of last year's World Scleroderma Day Campaign, Nadine Paciotti, simultaneously with our best wishes to this year's campaign manager, Mervat Gaafar. Some national stories from WSD 2016 follow in this newsletter. It was a wonderful campaign with a strong theme and with a truly beautiful film, an allegory of the dragon and the princess, as its centerpiece. Our thanks go to Alexandra Portales, who organised its development and its inspired direction. I hope we will go on using this moving film for a long while yet, even though we are creating a new one for WSD 2017 as part of the new campaign. Our 2017 slogan is very



strong: [Scleroderma Cannot Take My Smile](#). I would just like to remind all our member nations that FESCA funds the WSD campaign entirely, after raising the funds from our sponsors, but in order to apply for reimbursement of your national expenses, you must have followed the international campaign theme, design and materials.

It is such an optimistic time in SSc research. It now seems genuinely possible to find and use new medications. This year we created a new responsibility within FESCA: Research and Participation Manager. Joep Welling of the Netherlands took up the task, and his report follows here. As you read this, remember that because of the varied laws within our EU countries and the confidentiality agreements that we sign, we cannot write specifically about medications and what they do. However, this is not the case in the United States, and you will find a great deal of information about the same trials that we are partnering on the website of the US patient association. I also recommend that those seeking information go to the website

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www.clinicaltrials.gov. The trustworthy, objective information here lists 298 clinical studies for scleroderma, and 83 of these are open, including those in Joep's report. If you want to join a clinical trial, ask your doctor if you can. It helps others as well as yourself.

In addition to these clinical trials, FESCA is involved now in five competing proposals for EU funding, for research projects in which we would be a partner. The times are long gone in which patients were excluded from research, and we have an important part to play.

And what a part our people do play! If you have not already done so, check out the films about living with scleroderma made about our own two filmstars: Ilaria Galetti and Annelise Roennow. Many of our facebook pages and websites are now doorways into their homes and workplaces, where you can share the courage of their daily lives.

Speaking of websites, we have a wonderful new resource. The Project Scleroderma Patient Support App was launched a month ago and patients everywhere can download this app for free. It allows you to track and chart symptoms daily and keep a running diary of notes to share with doctors. A button within the patient resources tab of the app is dedicated to FESCA and there is a wellness tracker and a dosing reminder for medications. Information about downloading the app are on the FESCA website; it is completely secure and no information will be shared or sold.

All in all, we have much to be thankful for in the SSc world. It is more of a green Christmas than a white one this year in Europe, and let us hope that this is an optimistic sign for a happy new year, for a warm and sunny 2017, a year of good luck. I send you my very best wishes, and let us all smile together!



*FESCA members (l to r) Annie, Mervat, Beata, Nadine, Alexandra*



*Joep Welling*



*Dominique Godard, Nadine Paciotti*

**DISCLAIMER:** FESCA aisbl in no way endorses any of the medications or treatments reported in this newsletter. Information is provided only in a good-faith effort to share news. We strongly advise that you consult your doctor regarding any medications or treatments of interest to you, since every person reacts differently.



## This edition

Thank you to all for your contributions to this exciting edition of FESCA news. We would like to publish articles on events taking place in our member organisations' countries across Europe so send us your news!

Please send your contributions for future newsletters to [susanehoare@gmail.com](mailto:susanehoare@gmail.com).

## Research at FESCA

There is much research going on this year in the scleroderma area. Projects such as DeSScipher are continuing, despite the active grant period being concluded, due to the dedication of the doctors involved in such studies, who wish to continue to follow and record their patients for the study.

2016 brought new funding possibilities from the EU, in the form of new Horizon 2020 opportunities. FESCA cooperated as a partner in four last-minute funding requests for research proposals to send out to the EU. Some of these were new, updated proposals for the same research projects proposed at the last round. A total of 78 million Euro will be shared in the different fields of research! In January / February 2017 the main investigators will be informed whether their proposal will receive funding. As a partner in the successful project or projects, and as patients who will benefit from this research, we keep our fingers crossed for the TERGISS, ABISS, DESTINY and FAST proposals. We hope to be able to let you know at our AGM which of the projects has been successful.

In April and May this year some delegates of FESCA began a cooperative arrangement in the set-up for a new drug research trial by a global company. Sadly the company withdrew the European part of that research. At a later stage, we hope that Europe will be again involved. The research continues.

A research project that you already know of is the SENSCISS trial by Boehringer Ingelheim. FESCA has signed a Memorandum of Understanding together with Scleroderma Canada to act on a steering committee for this stage-three drug trial. Delegates from Europe, Canada and the USA are active on this advisory board to give the patients perspective. It is a so-called double-blind research trial, in which the real product will be given to 50% of the participant patients, and a placebo (a pill without medication) will be given to the other half

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Please see the FESCA website for more information, recognising that of course we sign confidentiality agreements for all the projects that we undertake, and for this reason cannot give you all the information that you might like.

A smaller project is a Canadian / European database development, designed to gather information about SSc patients. For this project funding has been requested.

The major SPIN project, about which we have often spoken, is progressing well and continues to receive funding as it expands.

There is much hope on the horizon!

*Joep Welling, FESCA Research and Participation Manager*

## **THE SPANISH SCLERODERMA ASSOCIATION AT THE OFFICIAL EVENT FOR RARE DISEASES DAY**

Every year, representatives of the Spanish Scleroderma Association are lucky to attend the official event organized by the Spanish Federation of Rare Diseases for the Rare Diseases Day, chaired by Her Majesty the Queen Letizia, who has always devoted herself to encouraging and giving visibility to those suffering from infrequent conditions, known as "rare diseases" and their families. Engaging as well the participation of many authorities involved with rare diseases conditions, it is an event aimed to spread the reality of all those families who live with a rare disease, claim their needs and promote solutions and appropriate care for the more than three million patients suffering from rare diseases in Spain.

This year, Alexandra Portales, president of the Spanish Scleroderma Association, is proud to explain how she had the opportunity to greet Queen Letizia and give her sunflower brooches. "It was really an honour for me to address Queen Letizia, thank her for her engagement with rare diseases and explain to her in few words the meaning of the sunflower symbol for scleroderma patients."





## HAND IN HAND FOR A BETTER FUTURE , CYPRUS

This year in Cyprus, we invited the press to a hotel for a “breakfast with the press”.

There, I talked about my personal experience. Also I said a few words about the slogan “hand in hand for a better future”. Then I explained the symbolic characters of the fairy tale about the Blue Dragon and the Princess for the film that was shown at the end.

A rheumatologist explained the disease and answered questions. The film was very moving and it was also transmitted on TV. I gave some interviews on radio and TV also. I think year by year more and more people learn about scleroderma. Awareness Day is more than essential.

***Despo Charalambous, General Treasurer of CYPLAR***



### FESCA AGM 2017

The 2017 FESCA Annual General Meeting will be held on Saturday April 8, from 9 am to 4 pm in Bucharest, Romania.



Nemzeti Scleroderma  
Közhasznú Egyesület

## HAND IN HAND FOR A BETTER FUTURE , HUNGARY

We had several activities in different parts of the country and in different media focus on the current campaign, Hand in Hand. We used the well created poster in our all medical clinics (four towns) placing them on the corridor walls, and the wonderful TV Spot in our website and Facebook page. We also had a PR article in one of the biggest women's magazine with the new Hand in Hand visuals. Beside the intensive media usage we also meet the public outside to raise awareness with the help of our members. Our aim was to go outside where we can get together hand in hand and be quite visible for other people. The main symbol, the sunflower was taken with us everywhere, where we made lots of creative photos with hands and sunflowers hand in hand. In three big cities where medical universities and clinics operate - Szeged, Pecs and Budapest - our Association organized World Scleroderma Awareness Day where the members called the attention to the disease in a way that they went around the city either by city train or boat or bus.

In the town of **Szeged** (29<sup>th</sup> June) our members raised awareness from the sight-seeing train with leaflets and sunflowers followed by a dinner.



In **Budapest** (2<sup>nd</sup> July) a boat trip was organised on the Danube to Margaret Island which is a big green area for recreation for the people living in the capital. Young and elderly people celebrated together World Scleroderma Day hand in hand at Margaret Island.



In **Pecs** (30<sup>th</sup> June) the group travelled to a Medical Bath Centrum, Harkany, where they spread the hand in hand campaign and got a full guide in the bath, what kind of treatments are available for people with scleroderma, and took part in a smiling yoga class. They then finished with a lunch and conversation.



Artistic photos “Hand in Hand for a better future” ... and our Vice President Anna Elek in a sunflower dress



**A sad farewell to our President Mr. Béla Szabó (1957–2016)**

Mr. Bela Szabo was a founding member of the Hungarian Scleroderma Association in 2005. For five years he acted as Vice President then from 2010 he became our President and led our Association successfully. In the civil life he was a programmer mathematician, an outstanding, great performer, communicator and organiser with a huge humanism who loved art, travelling, photography and wine. He loved to live. This 8<sup>th</sup> of October he left us forever leaving his beloved wife who was his true partner, friend and lover and his one and only daughter behind. Our heart goes out to them.



At the Danish AGM in 2015 it was decided that the Danish Scleroderma & Raynauds Association (Dansk Sklerodermi & Raynaud Forening) should change the name to Danish Scleroderma Association (Sklerodermiforeningen).

We were very happy to reveal our new logo on World Scleroderma Day. Our webmaster had been working with a local graphic designer, who worked following visual thoughts we had given her: hands, warm, community, sunflower, name. And she gave us this logo with the sunflower and hands turning towards it. The colours tells about warmth, encouragement, trust, kindness, energy, that we are here you!

Right after the summer holidays the Danish Scleroderma Association went on Facebook with the following address:

<https://www.facebook.com/sklerodermiforeningen/>

**Annelise Rønnow, Vice President, Danish Scleroderma Association**

### **Hand in Hand For a Better Future, Denmark 2016**

This year we arranged World Scleroderma Day in Aarhus at the Aarhus University Hospital on June 18th. Almost 60 people participated in **Hand in Hand for a better future**. Actually we had to bring in chairs from other rooms to make sure there was a seat for everyone.

The atmosphere was joyful and the day featured presentations by a doctor with speciality in lungs. She gave a very professional and competent presentation about lung problems in scleroderma. After her presentation the participants had many interesting questions.

After a nice lunch we went on with our surprise. We had invited Lulu to give a talk. Lulu is a hospital clown and told us about the important work a hospital clown takes on, especially at the children's hospital, but her work is actually useful for adults, too. Lulu arrived on a bicycle, probable the smallest bicycle in the world. Her message to all is: "EVERYONE has the right to be seen".

Next speaker on stage was a gastroenterologist who did a PhD thesis with the title "Gastrointestinal motility in patients with systemic sclerosis" in



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2011. You might think that speaking of a topic like digestive problems in scleroderma is difficult, boring and with lots of taboo. But this young doctor was so much alive in her presentation, and she spoke of digestive problems in a way that made everyone able to speak freely of GI problems of any kind. The doctor forgot all about her PowerPoint slides but nonetheless she managed to talk about everything - from the mouth to the bottom of the line, so to speak.

Our FESCA representative gave a presentation on things to use in everyday life to ease the challenges during the day. It was a mix of presentations she gave at the Systemic Sclerosis World Congress in Lisbon 2016 and Rome 2014.

All in all - the day was joyful with lots of happy people. The weather was sunny and warm. And we all went Hand in Hand for a better future. Next year the Danish Scleroderma Association is celebrating 10 years anniversary - with a SMILE.



## *World Scleroderma Day 2017 in Denmark*

### **In 2017 the Danish Scleroderma Association will celebrate its 10th anniversary**

Our plan for 2017 WSD is a conference for those with scleroderma and their relatives. Healthcare specialists are most welcome, too.

We have booked a very nice conference centre on June 24<sup>th</sup> at a place called Nyborg Strand. We want to have a panel discussion with three doctors: rheumatologist, dermatologist and gastrointestinal doctor. There will be no Powerpoint presentation but the three doctors will be willing to answer any questions from the audience. We have asked three very dedicated doctors from Denmark and our experience from earlier sessions indicate that the panel discussion will bring lot of smiles on the faces not only the audience but also the doctors.

With smiles we will make a bridge across the gap from doctor to patient and our goal for the day is to give hope and smiles to the patients and relatives, not to mention that we support the doctors' hard work to unveil scleroderma and ultimately get closer the cure. There will be a wonderful dinner after the conference and we are looking for an entertainment – a speaker of a kind who will show us the way to how to use laughter and smiles to help us to cope with illness and sorrow.

So the overall theme will be a positive approach to scleroderma, there will be a lot of smiles and hopefully doctors and patients will join hands with big smiles. We want a photo booth where the audience, hopefully with a doctor can have pictures taken – with a big smile. The pictures will be uploaded to our Facebook page during the day.



Spanish scleroderma patients and members of the Spanish Scleroderma Association (including the two regional scleroderma associations from Cantabria and Castellón) eagerly await each year the World Scleroderma Day, and all the activities specially organized with enthusiasm to spread awareness of scleroderma. And the result is always a bright and sunny wave of colour and zest for life.



The 2016 campaign *Hand in Hand for a better future* had a warm welcome among Spaniards, who actively participated in many activities throughout the month of June and strongly supported the Spanish version of the campaign on Social Media, *De la mano para un futuro mejor*. From the Spanish Scleroderma Association we are proud of the organic reach of our publications on our Facebook page, which raised more than 30,000 people only on 29<sup>th</sup> of June. A large variety of graphic material made that possible, especially the Blue-Scaled Dragon fairy tale video promoted by FESCA and recorded in Spain, the infographic about scleroderma and lungs done in collaboration with Boehringer Ingelheim, the daily life of patients with digital ulcers done in collaboration with Actelion, and of course the wonderful *hand in hand* campaign poster, as well as messages, photos and live videos of activities held in many cities.



*Conferences have been offered to patients thanks to the collaboration of renowned specialists and Hospital Universitario HM Sanchinarro in Madrid, Hospital Universitario Lozano Blesa in Zaragoza and Hospital San Pedro in Logroño.*

It had been an excellent opportunity to call the attention on scleroderma and our Association, to show the most real side of the disease for all those who did not know it, but also the enthusiasm and strength of patients fighting *hand in hand* against scleroderma, and the role of the Spanish Association among patients and society. And now, even if the world scleroderma day campaign had successfully finished, our work had not; our wish keeps on fighting against scleroderma *hand in hand*, throughout all the year, with all of you, like the princess of the Blue-Scaled Dragon fairy tale. A big thank you to all those participants, patients, doctors, friends, hospitals, companies.... all those who made possible to run the campaign and support us in our daily work and effort.

*Alexandra Portales, Asociación Española de Esclerodermia*





## Hand in Hand For a Better Future, FINLAND

The Finnish Scleroderma Association celebrated World Scleroderma Day by sending a pamphlet and a gift to members. Also we printed a brochure which presents the following: our association, Finnish Rheumatism Association, The Finnish Network for Rare Diseases, our rehabilitation center and FESCA.



There were three translated texts in the pamphlet (English=>Finnish). We had (as a donation from a pharmaceutical company) samples of two different lotions which could easily be included in an envelope.

We have received many thanks and appreciations from our members for the pamphlet, brochure and for the gift. Our members appreciate very much the translated texts.

FESCA - thank you for your support again this year!!

*Finnish Scleroderma Association Board of Directors*



## Hand in Hand For a Better Future, Belgium (French speaking)

For WSD in (French-speaking) Belgium, fitting in with the dates of rheumatologist consultations, we attended four University Hospital Centres on June 27th (in Bruxelles, Liège, Namur) and two Hospitals on June 29th (Tournai).

Volunteers gave information about scleroderma and sold our handmade products and others niceties, while specialists demonstrated capillaroscopy on people. It was very interesting for them. At the end of the day, everybody was tired but happy due to the interest people showed in scleroderma and the support of the medical team. We hope to continue next year.



## Hand in Hand For a Better Future, FRANCE

For the 8th World Scleroderma Day, regional delegates of the French Association – ASF – had planned awareness-raising events throughout France. Meetings between patients and doctors, Q&A sessions and experience sharing were organized in twelve cities: Bordeaux, Chenove, Clermond-Ferrand, Lille, Limoges, Paris, Marseille, Montpellier, Rennes, Reims and Vendôme.

In several cities, it was the first World Scleroderma Day event ever organized. This give us the opportunity to reach new patients and to start fresh collaborations with local medical teams. In Rennes, for example, the doctor and patient response was extremely large with 270 participants registered for the event! Several doctors from different specialties focused on the disease's complications they encounter in their fields.

In Paris, the program concentrated on the current therapeutic trials. It detailed the four phases of a trial and explained how patients can take part in a trial.

In Montpellier, a Q&A round table between doctors and patients was organized followed by lunch where patients shared their experience about the disease.

In Lille, the two educational therapy workshops based on the SLEROQUIZZ were extremely successful.

*Yanne Courcoux, ASF*



## **Hand in Hand For a Better Future, Switzerland**

### ***Overview of activities of the Swiss association for scleroderma patients around WSD 2016***

Within the realm of the international WSD 2016 campaign, in spring/summer in Switzerland we started a campaign which has been very happily successful and has helped a lot in creating more awareness for scleroderma. Although Switzerland is considered to be one of the smaller European countries in landscape and population, it is one where there are several population parts with more than just one spoken language. The major languages are German, French and Italian. So we had to consider this variation and the poster «Hand in Hand» has been voluntarily translated to all these three languages.

Having the Pharma firm Actelion as a valuable supporter of our engagement, we were given a list with over 500 national rheumatologists. We were able to send them the «Hand in Hand » Poster in order to present it in their offices and clinics as a supporting measure to our campaign.

The video « once upon a time with the « Scleroderma-Princess » has been shared in German as well as in French. It has found various distributional channels through social media, such as the association website, Facebook sites and by direct emailing to association members. Every member was kindly asked to share the video and the poster amongst family and friends and to help raise general awareness for scleroderma and to underline the need for support and assistance by all involved individuals and corporations in order to be able as a patient to manage life more easily despite the disease.

The overall conclusion was a satisfactory achievement of the targets of the campaign.

sclerodermie.ch

# Hand in Hand For a Better Future, Italy

For WSD, on 29<sup>th</sup> June, together, **four patient associations (Ails, Apmar, Assmaf and Gils)** supported the educational campaign promoted by FESCA.

There was a local TV interview (15 minutes) in a healthcare program to make people aware about scleroderma.



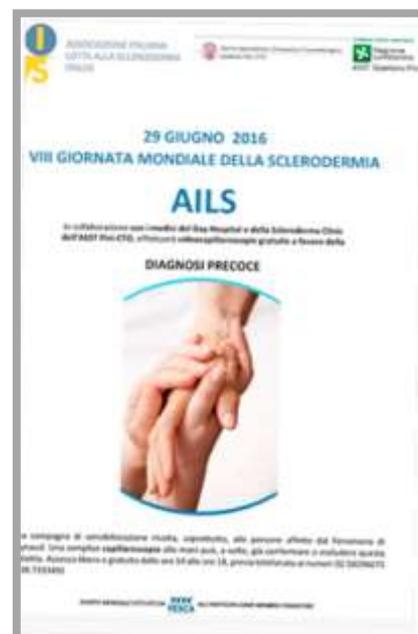
29<sup>th</sup> June WSD: press release of Prof. Armando Gabrielli's interview on scleroderma and research.

\*Prof. Armando Gabrielli, Dipartimento di Scienze Cliniche e Molecolari Clinica Medica, Università Politecnica delle Marche, Ancona.

Promoted by four patient associations (Ails, Apmar, Assmaf and Gils)

During World Scleroderma Day AILS promoted a campaign about the importance of early diagnosis and prevention.

At the scleroderma clinic dell'ASST Pini – CTO, there were free examinations all afternoon.



## Our First Family Day - Scleroderma & Raynaud's UK

On Saturday 2nd July we held our first family day bringing together families from across the UK and leading paediatric specialists.

The feedback suggests that the opportunity to connect with other families in similar situations was one of the most beneficial elements, as well as talking to clinicians in a more informal setting.

**"Thank you for arranging the conference and facilitating meeting other families going through the same journeys. It helps knowing we are not alone"**

**"Thank you again for arranging the day, more so because my daughter has had a really tough time this last few years with her scleroderma, and coming to the family day she was able to meet someone that is affected in a similar way that she is, and that has helped her a lot knowing she is not on her own. Both the girls have exchanged numbers and have been chatting every day since, this wouldn't have happened without the family day"**

Families shared with us some of the key issues of importance to them and what research questions we should be addressing for the future. Below are some of the questions that the children asked on the day:

"Does scleroderma hurt the brain?"

"Why does the skin look like it is burnt?"

"What does scleroderma do on the inside?"

We will be working with leading paediatric specialists to make sure families feel fully supported and future research focuses on answering their key questions.

A huge thanks to FESCA for supporting this event and improving the lives of families.



During June, at SRUK we launched our first public facing awareness campaign to highlight the signs and symptoms of Raynaud's and the link between Raynaud's and Scleroderma.

We know that Raynaud's affects an estimated 10 million people and for many people affected by scleroderma, Raynaud's was their first symptom. By getting to #KnowRaynauds we wanted more people to be aware of the support and choices available to them and know when to see a GP if other symptoms occur, to ensure early diagnosis of underlying conditions, scleroderma.

As part of this campaign we undertook research to find out how aware the general public were about the conditions and we were shocked by the results.

Despite being as common as hay fever and arthritis in the UK, over three quarters of people have never heard of Raynaud's or don't know anything about the symptoms

67% of people believe Raynaud's affects only one person in 5,000 or even less, when the actual figure is one in six, and just 4% are able to confidently identify the symptoms of Raynaud's, falling to 1% for scleroderma

Roughly one in five people would be embarrassed to say they had the conditions whilst 20% of people would be frightened to touch someone with Raynaud's and 24% someone with scleroderma

To tackle the lack of awareness and understanding we worked with Unite (medical union) and a range of

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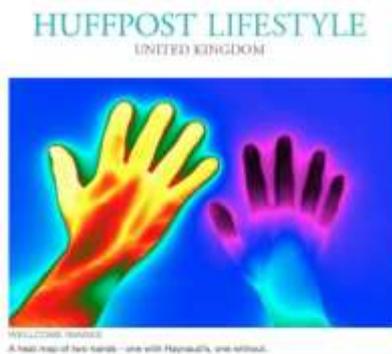
press outlets. We featured as Unite/Community Practitioners and Health Visitors Association's (CPHVA) charity of the month providing information via a briefing, video and Twitter Tuesday to their 100,000 members.

As we all know, there needs to be more awareness raised amongst health professionals but during our Twitter Tuesday the comments we received showed just how little awareness there is.

Throughout June we featured in a range of local and national press using our research findings and case studies to show why it is important to increase awareness and understanding.

Key features include the Huffington Post, Express Online, Yours Magazine and Woman & Home.

**Amy Baker, SRUK**



**What is scleroderma?**

Only a small number of patients with Raynaud's go on to develop a more serious connective tissue disease, scleroderma.

However this condition can cause disability and can even be life-threatening, which is why it's important to be diagnosed early.

Scleroderma is a rare, chronic disease of the immune system, blood vessels and connective tissue.

It is an autoimmune condition, meaning the immune system becomes overactive and attacks healthy tissue in the body.

The name of the condition comes from the Greek, 'sklerō' for hard, and 'dermis' for skin. This hardening of the skin can be one of the first noticeable symptoms of the condition, as the body produces too much collagen.

This excess collagen can affect the skin, joints, tendons and internal organs.

It causes swelling and stops the affected parts of the body from functioning normally.



New research from charity Scleroderma and Raynaud's UK (SRUK) has revealed that thousands of people across Glasgow could be living with a condition that they know little or nothing about, and therefore not accessing the help they might need.

In fact Raynaud's, sometimes referred to as vibration white finger, is as common as hay fever or arthritis in the UK, yet over three quarters of people in Glasgow (77 per cent) have never heard of it or know nothing about the condition. Some Raynaud's patients go on to develop a more serious connective tissue disease, scleroderma - which can cause disability and can be life-threatening - so it is important to pick this up early.

As a result, SRUK are launching a new campaign today to help people in Glasgow to spot the signs of these conditions and encourage them to seek advice and support if needed.



Caroline Goldstein, from Bristol, a mum and former hospital doctor, began experiencing symptoms for Raynaud's phenomenon in her early twenties at medical school after finding her hands and feet would become extremely cold and painful.



According to the NHS, as many as 30 million Brits suffer from Raynaud's disease, and most people with the condition don't know they have it.

The charity Scleroderma and Raynaud's UK (SRUK) state that Raynaud's disease occurs as often as hay fever and arthritis, but as few as 4% of the population have even heard of it.

In response to the public's lack of awareness, SRUK have launched a new campaign to educate people on the cause, symptoms and treatments for Raynaud's and scleroderma.

**What is Raynaud's disease?**

It is a condition that affects the blood supply to the extremities, in particular fingers and toes, and can be triggered by anxiety, stress and exposure to cold temperatures.

I am very glad to inform you that at November 18, 2016 in the presence of princess Beatrix of the Netherlands, NVLE and Scleroderma Framed attended today's conference to celebrate the 90th anniversary of the Dutch Arthritis Society. It ended spectacularly with a personal speech of Dr. Bernelot Moens who also announced *the ARCH project*. Six million euros will be available to improve the care for #scleroderma and other systemic autoimmune diseases in the next years! We're happy and that, together with the NVLE patient organization, we were able to celebrate this great news. To be continued...

*(Translation of the text above by Dr. Linda Kwakkenbos of the McGill University, Montréal with expertise in Health Psychology/photos Scleroderma Framed)*

The committee of Scleroderma/MCTD of the NVLE (=our national patient organization) which I also actively organize, we are busy with the Scleroderma Day in June 2017. We finally have a very good location in the middle of the Netherlands that fits the theme, we expect about 200 people. Now we are thinking about a special name for the theme and which specialists we are going to invite and the program has yet to be classified. The developments concerning the ARCH project will be included in the program because the chairman of the NVLE/ Margot Wijbrands, the chairman of our committee Scleroderma and founder of Scleroderma Framed / Jessica Thonen-Velthuizen and I (Linda Schraven) will be involved with this project in the Netherlands!

Furthermore we are again very excited to offer scientific but also relaxing program to people in the Scleroderma congress 2017, next time I can tell you all firmly about it !



As a part of World Scleroderma Day on June 29, 2016. Scleroderma / MCTD Committee organized not one but two meetings (to accommodate people in the north of our country and in the middle) in a cosy café for patients to talk with each other and time to ask questions to medical professionals. This year we gave special attention to patient contact!

We've sent the poster to several medical professionals and used it together with the video for social media. There were a lot of people aware of the enormous publicity for scleroderma this year !

We as a committee scleroderma / MCTD, look back with a good feeling. The reactions were positive, the atmosphere was good, the location was excellent and the presence and answering various questions by medical experts was very positive.

The Scleroderma Day in June 2016 was very good, the people had to fill in a questionnaire that we have send all the people after the meetings and the average grade was an eight !

**Linda Schraven, NVLE Netherlands**

# News from Sweden

## New Swedish patient association for systemic sclerosis starting up!

We've been working for a year to start a patient association for people with scleroderma together with Reumatikerförbundet.

We want to support newly diagnosed people, arrange lectures, inform our members about research and new findings.

Our first national annual meeting will be on the 25th of March next year in Uppsala. We're looking forward to that!

**Monica Holmer**



## Scleroderma app – now available for download

Throughout 2016, Project Scleroderma (<http://projectscleroderma.com/>) has been brainstorming new and innovative ways of helping the scleroderma community, in addition to the awareness component which was their first focus. Now they have officially launched the Project Scleroderma Patient Support App., in conjunction with FESCA, so that you and scleroderma patients everywhere can download this app for free at any time.

The Project Scleroderma Patient Support App, among other features, allows patients to track and chart symptoms on a daily basis and keep a running diary of notes to share with their physicians. It offers a space to interact privately and securely with other scleroderma patients, and will serve as a hub for patient resources and educational videos.

Project Scleroderma promises to update this app continually, and add useful content on a regular basis. Its main purpose is to simplify the daily experience for scleroderma patients as they tackle everyday challenges, to help ease the emotional stress that is a part of chronic illness, and to help patients who are newly diagnosed to better navigate this new and overwhelming diagnosis.

Also included is a wellness tracker that allows patients to track their overall well-being on a daily basis, and a dosing reminder for patients to set for their medications.

**The button for FESCA** is in the patient resources tab, and contains the link for our Facebook and website and video. The app is completely secure, and HIPPA compliant. No information will be shared or sold. It is strictly for the benefit of the patient. We will periodically be running surveys through the app to see how people are feeling about it, and to find ways in which they can help improve it.

Both FESCA and Project Scleroderma are committed to supporting the scleroderma community in as many ways as we can, in addition to our ongoing mission to dramatically increase the global level of awareness for this disease. We hope that this app will truly help scleroderma patients from every part of the world to simplify their experience and to connect with others who are battling this disease.

Visit: <http://www.fesca-scleroderma.eu/wordpress/?p=875>

## 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>  
[cyplrar@cytanet.com.cy](mailto:cyplrar@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>  
[marjo.makela@ebaana.net](mailto:marjo.makela@ebaana.net)

### France

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

### Hungary

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

### Ireland

Raynaud's & Scleroderma Support, 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.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)

### Germany

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

### Norway

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

### Poland

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

### Portugal

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

Associação Portuguesa de Doentes com Esclerodermia  
<http://associacaoapde.wixsite.com/esclerodermia>  
[associacao.apde@gmail.com](mailto:associacao.apde@gmail.com)

## 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:

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7500 TOURNAI, Belgium

President: Ann Tyrell Kennedy, Ireland

Vice-President: Beata Garay-Toth, Hungary

Secretary: Alexandra Portales, Spain

Treasurer: Despo Charalambous Demetriou, Cyprus

Counsellors:

Kim Figelstone, U.K.

Nadine Paciotti, Switzerland

Annelise Rønnow, Denmark

Joep Welling, Netherlands

Newsletter Editor: Susie Hoare, U.K.

### 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

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)