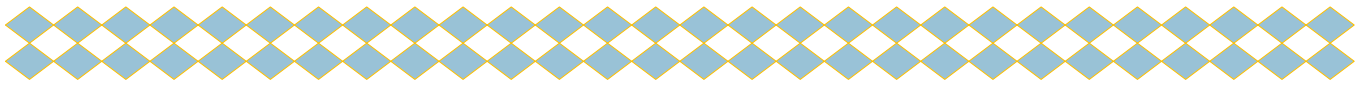


FESCA NEWS

News from the Federation of European Scleroderma Associations, Winter 2014-5



Welcome from our President

Dear friends,

In this newsletter, I have both bad and good news for you. I have to share with you first of all our deep sadness at the loss of two of our FESCA representatives. Two long-time members have this autumn lost their battle with scleroderma. Both had been ill for a very long time. Catherine Van den Bosch, our beloved friend and FESCA secretary, a member of our Board almost since the beginning, had been unable to travel due to her PAH for several years, and so many newer members amongst you may not even have met her. Surely, however, you have heard us speak of her. She is deeply mourned by us, who love her like a sister. She and her husband live in Belgium, where she did much valuable work for FESCA, and acted as our legal counsel.

Our second loss is of Anne Mawdsley, who has been an indefatigable fighter for people with scleroderma for the majority of her very long life. She has probably done more for the cause of those with scleroderma, and raised more money for scleroderma research, than anybody else in the world. Despite the heavy burden of her scleroderma, Anne lived well into her seventies, founder and leader of what I believe was the first Raynaud's and Scleroderma Patient Support society in Europe, the RSA in the UK. Her life's work was raising awareness and support.

Please do not hesitate to get in touch with any of us on the FESCA Board if you want to

talk about this or anything else. All we can do to lessen the sadness is to celebrate these two lives well lived, and to pursue our goal of better treatments and a cure.

Now for the good news. Several extremely promising new treatments for systemic sclerosis are in development, some of them already entering phase 3 in clinical trials, because they include drugs already in use for other conditions. FESCA is directly involved as a partner in all such projects, and we are looking for volunteers to be the contact point for some of them.

These are exciting times, as several programs that focus on the development of treatments of systemic sclerosis have been submitted to the EU's HORIZON 2020 call for rare diseases. Significant research grants will be given. A first selection round is currently ongoing, and FESCA is hopeful that at least one of these proposals will be invited into the second round, with final funding decisions taken in late spring this year. This grant would be a major step forward.

In addition, other new EU projects that aim to develop standards,



Editor's note

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 susie@sclerodermasociety.co.uk.

scores and impact studies have received funding and are proceeding. Development and validation of the EULAR Systemic Sclerosis Disease Impact score (EULAR ScleroDI), this month received EULAR funding, and the New Recommendations for Treatment of Systemic Sclerosis, also funded by EULAR, are developing fast.

All this is wonderful, optimistic news and I look forward to telling you more soon. Don't forget that the FESCA AGM takes place in Amsterdam 27-29 March 2015 (meeting all day 28/03/15), and that the 4th World Scleroderma Congress takes place in Lisbon and will run from 18-20 February 2016.

With warmest wishes to you all, Annie

STOP PRESS!

The following article was published in EULAR PARE'S Breakthrough Magazine, January 2015

Introducing FESCA

The Federation of European Scleroderma Associations (FESCA aisbl.) has been unifying the goals of patient support and advocacy groups for 8 years now. An umbrella group of 24 patient organisations in 19 countries, it shares awareness-raising campaigns, information, and practical strategies, not only within Europe but in the Americas, Australia, and elsewhere. As an initial group of 7 associations, its first task was to create a World Scleroderma Day, then a World Scleroderma Congress. Currently, a major task is to partner research projects with the World Scleroderma Foundation (WSF). Scleroderma is a rare disease, and effective research requires a wider consortium of patients than can be found in one country. It is our role to provide access to a sufficiently large base for clinical research and to spread information among patients concerning new therapies.

Fourth World Systemic Sclerosis Congress

The Patient Programme for the Fourth World Systemic Sclerosis Congress will consist of interactive sessions of lectures and discussion between consultants and patients. Lectures will be given in English but translated into major audience languages. Some topics will be covered in smaller groups and in different languages. Experts will answer questions such as: What are the options in treating SSc? Is the heart involved? Why is breathing so difficult? What can I do to help my digestion problems? What can be done about the pain in my feet? Should I consider a transplant? Can I try to get pregnant safely? What new therapies are available now? What are researchers and FESCA doing for us? How can I cope with my fatigue? Can I get help as a man with SSc? How can my family and I deal with depression? How can children with SSc learn to cope? The patient congress will also include interactive exercise and breathing sessions, plus a round-table networking meeting for leaders of patient groups the afternoon before the congress, and plenty of networking opportunities during it.



World Scleroderma Day



Cyprus

In Cyprus, this is how we celebrated World Scleroderma Day in 2014.

On Friday 27th June, I spoke to the national radio (CYBC) about the disease, and how to cope with it in everyday life with good self-management.

We talked about the importance of celebrating World Scleroderma Day, and the plans we had for the day. That evening, we had a night dedicated to people with scleroderma accompanied by someone else (husband, friend, relative). It was a dinner for encouraging pws (people with scleroderma) to socialize and enjoy their lives. They were given a small gift at the end.



On Saturday morning volunteers, mostly family and friends of pws distributed leaflets with this year's theme, "Turning towards the Sun", together with a real sunflower. Our location was the centre of the historic centre of Nicosia. Despite the heat that day (38 degrees Celcius) we did it!

Despo Charalambous, General Treasurer of CYPLAR





News from Norway



We are not more than 200 people in our small group (under 500 in Norway). Lately we have seen more men than usual! We have a lot of contact with the members. Lack of money prevents us from travelling around although we are trying to have one of our board meetings outside Oslo (once a year). We have only 2-3 meetings a year!

Our activity is mostly in the Oslo area as most patients live here. We arrange about 10 meetings a year and the feedback is very good.

Then we invite the members in the district to join us for a lunch or just a coffee to exchange experiences about scleroderma. We call it "likepersonstreff" (which is Norwegian for patient peer meeting). It is very informal and nice where we talk about everything and where we understand what the other person is saying!

We have contacts in half the counties in Norway and the members are welcome to call them.

Every 4th year we arrange our conference for members. This is very popular as we always seek to find the best speakers on scleroderma which is not difficult as we have some a very good staff of doctors at the University Hospital in Oslo (Rikshospitalet). We just need to finance the conference. Unfortunately for us in Norway, we are not allowed to do fund raising but have to seek from funds.

We are very happy to be in Fesca as we get a lot of information from you. We will send one representative to the FESCA AGM in Amsterdam in 2015.

Hild Fronth
Diagnosegruppen Sklerodermi, Norway
Norwegian Scleroderma Group

Norwegian celebrity gets scleroderma

The Norwegian celebrity Gunhild Stordalen has recently been diagnosed with **diffuse scleroderma**. Both Gunhild and her husband Petter Stordalen are extremely well known in Norway. They therefore chose to be open about Gunhild's severe diagnosis from the very beginning. And that caused every media – papers, TV channels, radio and magazines – to deal with the news.

Gunhild and Petter only one interview, and media are now hunting for other sources. Facts about our rare diagnosis are being quoted from Wikipedia, encyclopedias, our website and others. Several doctors and experts have been interviewed in TV and papers, and so has Hild Fronth, the leader of our group. Hild did it very well – we are really proud of her. She managed to calm the fuss down a bit, emphasizing that we are many people who are living quite well with our diagnosis

We are very sorry for Gunhild of course, but scleroderma has now become a front page case. We already see a trend of getting contacted by new patients. Many are alone, and many are afraid, but now we are able to reach them and hopefully give them a little help.

As mentioned above Gunhild got the aggressive type of scleroderma. She got the diagnosis at Rikshospitalet – the Chief Hospital of Norway. Gunhild is a doctor herself and was immediately aware of the seriousness of the disease. She and her husband wanted a second opinion and contacted one of the world's premier experts on systemic scleroderma, Mr. Thomas A. Medsger at Scleroderma Center in Pittsburg, USA. He advised Gunhild to go for an experimental treatment given by a hospital in Utrecht, the Netherlands. The treatment called **The Big Gun** is a *high dose chemotherapy treatment of the stem cells, or autologous bone marrow transplantation*.

The treatment is in no way harmless. It has many side effects including a mortality of 10%. Nevertheless, Gunhild is a young woman of 35, willing to try whatever it may be to avoid living with a disabling and painful diagnosis for the rest of her life. Her three months of treatment in Utrecht have already started. We are thinking of her, hoping for the very best both for Gunhild Stordalen and also for the sake of scleroderma.

Below we enclose some links to Norwegian websites. We know you don't understand the language, but it will give you a hint of how big this is in Norway just now.

Liv Kristiansen

Member of the board of the Norwegian Scleroderma Group

Hild Fronth: Jeg skjønner at Stordalen er redd (*Hild Fronth: I understand that Stordalen is afraid*)

<http://www.vg.no/nyheter/innenriks/hild-62-har-ogsaa-sklerodermi-jeg-skjoenner-at-stordalen-er-redd/a/23341359/>

Ny forskning viser lovende resultat (*New research shows promising results*)

<http://www.vg.no/nyheter/innenriks/nye-studier-viser-lovende-resultater-for-sklerodermi-pasienter/a/23341308/>

Spørsmål og svar om sykdommen Aftenposten 23112014 (*Questions and answers about the disease*)

<http://www.aftenposten.no/helse/Sjelden-sykdom-som-angriper-mange-organer-i-hele-kroppen-7797301.html>

Slik er sykdommen Gunhild Stordalen lider av -Vg Tv (*Such is the disease that Gunhild Stordalen suffers from*)

<http://www.vgtv.no/#!/video/104230/slik-er-sykdommen-gunhild-stordalen-lider-av>



Országos Scleroderma
Közhasznú Egyesület

World Scleroderma Day 2014

This year was an unusual way of celebrating World Scleroderma Day in Hungary. It was now about outside activities and arts, combined with sunflowers as this year's main slogan suggests: "Turning towards the sun". The Hungarian Scleroderma Association had three cities where our sets of members and supporters get together and increased awareness of scleroderma.

In the **city of Pecs**, members of our Association organised an excursion to the main hill of Pecs, Tettye, which is well-visited by people from the city and tourists. They had a guide, visited a nice church and the surroundings. They took sunflowers with them, the international symbol of scleroderma in order to let other people know about the disease. They took several photos from the event.

In the **city of Szeged** the members organised a boat trip on the river Tisza which flows through the city. It was good awareness-building celebrations since people could see the special sunflower decoration on the boat.

In **Budapest**, the members organised World Scleroderma Day around art. The Hungarian National Gallery (situated in the Castle Hill inside the Palace) provided us with a big room where the paintings are usually restored, with a beautiful view to the Danube and the whole city. The main topic was Paul Klee and the sunflowers. Two nice art ladies helped us and held a lecture about Klee's artistic work with the main focus on sunflowers. Then our task was to make our own sunflower mandala or other work. We could choose among several painting techniques and art methods. Water painting, textile, and other techniques. First we were a bit worried about how to start and what to do, but our helpers gave good advice. Finally amazing works were born - even we did not know that we were able to do that and we were so proud of ourselves. The works and all the other photos can be seen here: <https://www.facebook.com/OrszagosSclerodermaKozhasznuEgyesulet>

Beata Gary Toth, Hungarian Scleroderma Association



Denmark

Dansk Sklerodermi & Raynaud Forening

In Denmark, World Scleroderma Day was marked on Friday 27th June with a small conference. Each year we change locations - this year was held in Aarhus and next year will be on the opposite site of the country, in Copenhagen.

50 patients, health care staff, family and friends attended this conference which included three very interesting lectures from three doctors who work at our two specialist scleroderma centres in Denmark. Besides treating scleroderma patients, they do research within scleroderma - in overall they are very dedicated to helping scleroderma patients, and to finding the best treatment for each patient.

Before the lectures began, the Danish Scleroderma and Raynaud's Association hosted a very nice lunch. The three lectures were very different: the first lecture was with Klaus Soendergaard who gave information on the updated 2013 ACR/EULAR Classification Criteria for scleroderma. According to Klaus this is very good news as it can help with much earlier diagnosis and thus treatment. The second lecture was a very passionate lecture by Anne Braae Olesen, who talked about new treatments within scleroderma. The goal is to find the right treatment for the right patient. Also it is a wish to have a greater focus on each patient, not only as someone having scleroderma but also making sure that persona can maintain a good quality of life with scleroderma. The third lecture was by Mette Mogenssen who spoke about having scleroderma as a young person and continuing to have a good life with work, a partner, pregnancy and sexual life. Mette ended her lecture with the following quote which is very important to keep in mind: beauty comes from within; embrace life and keep loving life.

A new feature we introduced this time was "Ask the doctor" - here we had a session where you could ask the doctors about anything. And many did!

The afternoon took place with positive minds, and with many laughs and networking, even though the topic was sometimes hard. And the weather was wonderful - we all turned towards the sun.



*Annelise Rønnow,
Danish Scleroderma
and Raynaud's Association*



World Scleroderma Day

Switzerland



On the occasion of World Scleroderma Day, we organized an information day and held our 4th AGM.

Our wish during these days is to bring to our members and all those affected or interested by scleroderma:

Aid, comfort, support and / or information

In addition, we contacted several specialized magazines and the press throughout Switzerland to publish the poster designed for June 29th 2014.

At our information day, the first lecture "stem cells transplantation" was presented by Prof. Walker from Basel and then we heard a moving testimony from someone who had received stem cell treatment in 2013.

The second theme of the day was "breathing exercises" presented by M. Pierre-Alain Wieland. Through simple but effective exercises with an elastic band, each person could learn exercises and repeat them regularly at home.

This day was held in French and German. Then we had a meal together and ended the day with our annual general meeting.

Nadine Paciotti

Swiss Association of Scleroderma Patients



World Scleroderma Day

Spain



2014 WORLD SCLERODERMA DAY IN SPAIN

The 2014 World Scleroderma Day celebration in Spain had been a new occasion for scleroderma patients to show that they do not give up. As in previous years, there had been many who have participated from their cities and contributed their grain of sand to increase scleroderma awareness: patients, relatives, friends, institutions, showing all of them their willingness and enthusiasm to celebrate this special day, joining us in turning towards the sun.

Since the beginning of June, several patients and representatives from the Spanish Scleroderma Association had given interviews to the media, encouraging the publication of articles, radio broadcasts and short informative broadcasts public transport video information screens of some large cities.

Others have been involved disseminating information in health centers, hospitals and public places: leaflets, posters, informative desks. All occasions were good to spread awareness and all those who participated in the campaign knew how to make the most out of every opportunity and moment, even small actions. A great example is the initiative of a patient, who decided to put leaflets in the cafeteria of the train in which she was travelling from Cadiz, in the south of Spain, to Madrid.

All those who decided to join us in Las Rozas, in the outskirts of Madrid, on 28th June spent an intense day, planned around a conferences program and the General Assembly of the Spanish Scleroderma Association. Nearly 100 people attended interesting lectures, moderated by local authorities councils, about the disease, the situation of research and personal experiences. There had also been time for debate and participants interaction. The lunch break is always a long awaited moment, as a great opportunity for participants to contact each other, share experiences and initiatives, some of which are the first steps of new projects and activities.

Others preferred to celebrate 29th June and spread scleroderma awareness with a contagious zest for life: music and dancing. All those who were in Pamplona on 29th (worldwide famous city for the running of the bulls during its festivities), could join the Scleroderma group who was dancing in the main place of the city.

Thanks to the courage of scleroderma patients, and to the efforts of all those who have helped us in any way, all these activities have contributed to increase scleroderma awareness. And now more than ever, WE DO NOT GIVE UP!

Germany celebrates 30-20-10-1



We couldn't have better done justice to this year's motto of the WSD's "Turning towards the sun" than celebrating a four-fold anniversary of the German Scleroderma Self-Help Association on this wonderful sunny 18th/19th July 2014.

On the occasion of the **30** year- Sklerodermie Selbsthilfe e.V. (SSh), **20** year Deutsche Stiftung Sklerodermie (DSS), **10** year Deutsches Netzwerk für Systemische Sklerodermie e.V. (DNSS) and **1** year Edith Busch Stiftung (EBS), the SSh extended invitations to join a festive ceremonial act and a Scleroderma Symposium at the historical Juliusspital in Würzburg.

The evening on the first day started with a social get-together with music, a historical perspective of art of the late work of Paul Klee and a tour through the wine cellar of the Juliusspital founded in 1576.

The SSh chairwoman, Emma Margarete Reil, hosted the evening emphasizing that the self-help group hasn't just been lucky with their successes since luck doesn't appear from nowhere, but settles on well cultivated grounds. She thanked all volunteers for 30 years of loyalty and support whether doctors, team leaders or management in the institutions, since without these people the success would not have been possible.

All people celebrating the anniversary briefly introduced their institutions, their work and the successes and accomplishments connected with it. The SSh chairwoman emphasized that the guiding principle of the SSh "demand and support" which equally includes physicians, scientists, affected people and the industry, finally led to good results of the medical physicians and the scientists for those affected and the self-help group.

The chairman of the German Scleroderma Foundation (DSS) Prof. Thomas Krieg referred to the remarkable success of the Foundation, which was once founded by the self-help group. Continuous bids and support for scientific research helped to make Scleroderma more known and respectively aroused interest in universities, clinics and the industry.

Almost 50 research projects that were subsidized by the DSS with just short of one million Euros essentially contributed to the fact that affected patients are diagnosed much quicker today and they also receive a much better treatment.

The chairman of the German Network for Systemic Sclerosis (DNSS) Prof. Nico Hunzelmann reported on the advantages of the network (quick exchange of knowledge, outstanding database, better possibilities for spe-



cialization etc). He was also able to confirm that the data of the German Network corresponds with that of the European (EUSTAR) network taken as proof for a correct approach and that patients evidently profit from these networks.

The Edith Busch Foundation (EBS) as the youngest in the round celebrating the anniversary was introduced as a foundation solely dedicated to scleroderma. The chairmen of the EBS, Dr. Ulrich Schanbacher and Dipl. Kfm. Martin Bäßler first of all thanked for the “well -tended Scleroderma ground” (which they ultimately profit from) with a check over 3.000 € to the self-help group. The EBS facilitates a good cooperation between all institutions which all parties involved profit from.



The symposium on day two was dedicated to the latest scientific research in regards to the form of appearance, diagnostic and therapy of systemic and circumscribed scleroderma as well as the advantage of patient registers. Some well-known public figures such as Prof. Frank Wollheim from Lund/Sweden, Prof. Nico Hunzelmann from Cologne, Prof. Gabriela Riemekasten from Berlin, Prof. Michael Pfeifer from Regensburg, Prof. Ulf Müller-Ladner from Bad Nauheim and Frau Dr. Pia Moinzadeh from Cologne attended the symposium.

The day ended with the awards presentation of research and author prizes that were posted by the Foundations and the Scleroderma self-help association.

Research prizes went to:

Dr. Christian Beyer, Erlangen, for his research work: *“Stimulation of the soluble guanylate cyclase (sGC) inhibits fibrosis by blocking non-canonical TGFβ-signaling”* (Deutsche Stiftung Sklerodermie)

Dr. Angela Kill, Berlin, for her research work: *“Autoantibodies to angiotensin and endothelin receptors in systemic sclerosis induce cellular and systemic events associated with disease pathogenesis”* (Edith-Busch-Stiftung)

Author prizes went to:

Anna-Lena Dohrmann, Leipzig, for her work: *“Eine Haut wie zu kurze Handschuhe”* and Emma Margaret Reil (Heilbronn) for her booklet: *Fußprobleme bei Sklerodermie* (Sklerodermie Selbsthilfe e.V.)

These days clearly demonstrated once again how a successful cooperation between committed self-help, scientific research and the generous support of foundations benefits affected patients.

The German Sklerodermie Selbsthilfe e.V. exists since 1984 and can be proud of what it achieved but won't rest by noting this in the footer of their flyer: **“We've continuously followed our way – we've made a difference and achieved a lot. We will not rest but go further and will not give up until we've reached our goal.”**

Gabriele Niehaus
Sklerodermie Selbsthilfe e.V.
Regionalgruppe München



To celebrate World Scleroderma Day a variety of events were held throughout the week. On the 3rd July the Scleroderma Society held their first ever collaborative event with the RSA in partnership with the Royal National Hospital for Rheumatic Diseases, Bath (read more on the next page!) This event was held in celebration of World Scleroderma Day and was an educational event for both patients and clinicians.

Bright and Blue (photos left):



The Scleroderma Society also went 'Bright and Blue' for World Scleroderma Day. We were delighted to see so many wearing blue for the occasion - Salford Royal took 'blue' to the next level by taking a photo with a thermal imaging camera. Through wearing blue you raised awareness of this rare condition and awareness leads to better education and understanding of this condition. Thank you to everyone who supported the weekend and your fundraising will be used to develop further support resources for individuals and their families.

ART Competition (photos right):

Thank you to everyone who took part in this year's art competition entitled "Turning toward the sun." We were really pleased with the amount of entries received and this led to a difficult decision for our judge, Alan Brain. Alan is an accomplished artist and teacher working within the field of abstract art.

Aspa Palamidis was awarded our first prize. Aspa spoke of her painting: "It's a scene of the River Thames at Kingston, in loving memory of my husband George. George was particularly fond of the river and asked me to take our son there the day before he left us. I hope you see something in it too; it means a lot to us."

Megan Hewitt was awarded our second prize of a Cass Art goodie bag. Megan's mum, Melanie, said, "As I have scleroderma along with lupus my daughter, Megan, wanted to do a poster. The idea was that I always feel better with the warmer weather so she thought if I flew up to the sun I would come down all better." Megan was thrilled to be awarded second prize and even took her drawing and goodie bag to school for show and tell.



United Kingdom

World Scleroderma Day Celebration, Thursday 3rd July, RNHRD, Bath

The World Scleroderma Day Celebration for 2014 was held at The Royal National Hospital for Rheumatic Diseases, Bath On 3rd July with the help of Dr. John Pauling, Consultant Rheumatologist.



To mark this occasion and to celebrate the life of Paul Klee, the famous artist who died from the disease, The Scleroderma Society and Raynaud's & Scleroderma Association jointly organized an educational event to raise awareness and help people understand more about the condition.

45 people with Scleroderma and/ or RP and associated conditions, along with family and friends attended a morning session and heard talks from Dr. John Pauling on the link between Scleroderma & RP, from Dr. Victoria Flower, Specialist Registrar on current and future treatment options for scleroderma and Consultant Specialist Nurse Sue Brown talked about self-management of the condition and how best to handle your own condition by 'Listening to your body!'. Attendees enjoyed the opportunity to ask questions throughout the presentations and meet the team at Bath, over a buffet lunch.



In the afternoon there was a series of clinical sessions. The first from Julie Frank, dietician provided information on eating techniques whilst getting the benefits from eating little and often. Jayne Masters, Physiotherapist and Lisa Small, Occupational Therapist talked through physiotherapy exercise, the boom and bust theory, general well being practices when suffering with fatigue and other coping strategies. 'The meeting was very informative and explained in a way which was very understandable' said one of the delegates.

Clinicians and Health Professionals from the South West attended the Lecture Hall in the afternoon with a talk on pathogenesis from Dr. Harsha Gunawardena from North Bristol NHS Trust, a view of PAH and other clinical features from Dr. Gerry Coghlan from The Royal Free Hospital London and a synopsis on practical management of Raynaud's Phenomenon and systemic sclerosis by our host.

Dr John Pauling said 'We are delighted to be hosting this event for our patients and clinicians whilst sharing our knowledge of the diseases. We had some fantastic speakers and presentations sharing issues and successes within this field and everyone who attended seemed to find it engaging and worthwhile and it was a pleasure to host this exciting event here at the RNHRD and we would very much like to do so again.'

Report on Scleroderma Day 2014 Raynaud's & Scleroderma Ireland

World Scleroderma Day was celebrated in Ireland with two events. One was a repeat of last year's very successful and enjoyable Afternoon Tea Party. We had a new venue for this, the very popular and fashionable Westbury Hotel, off Grafton Street in Dublin.

George Hook, radio presenter and popular rugby pundit, gave a light-hearted speech; the hotel provided a delicious selection of savouries, scones and cakes, washed down with a choice of red or white wine and regularly replenished pots of tea and coffee.

Claire Brennan, a member of Raynaud's & Scleroderma Ireland spoke about what it is like to live with scleroderma and her talk was inspirational and very moving.

We also ran a public event on busy Grafton Street on the Saturday morning. This was called #UseYourHands and involved a huge canvas on which members of the public were asked to put their painted hand print on the canvas. We printed a large poster using Paul Klee's painting and used this to advertise the event.

Paul Klee's painting was used to produce notelet cards for "thank you" or other messages and these have proved very popular.

Photos:

Radio presenter George Hook and his grand-daughter Maggie McGill getting their hands painted for #UseYourHands

Tasty treats served by the Westbury Hotel for Afternoon Tea on World Scleroderma Day 2014



EULAR Autumn conference in Zagreb

The EULAR Autumn Conference is an annual meeting of people with arthritis/rheumatism in Europe organised by the EULAR PARE Standing Committee. The conference's main goal is, that is a site for specialized training, education and networking provided to the member countries by the standing committee.

On November 7th to 9th, we attended this year's annual PARE AUTUMN CONFERENCE along with representatives from many European organisations within the EULAR organisation. The workshops were hosted by the Croatian League Against Rheumatism. Most workshops took place on November 7th and 8th.



The presentations and workshops were developed to inform, empower and motivate EULAR member organisations of PARE by providing delegates with the opportunity to learn from experts and each other.

The conference on the subject of “Healthy Ageing and Rheumatic and Musculoskeletal Diseases (RMDs)” offered insight into topics as rehabilitation in RMDs, how to use recommendations to improve health care, what organisations can do to help people enjoy healthy eating, social media, children and young people with RMDs, how to develop a communications strategy as well as how to write and submit an abstract for the EULAR congress.

None of us had been to EULAR Autumn conference before, so it was very interesting to meet with other organisations and learn how they work within the chosen subject. Each day you were to go to two chosen workshops. Annelise went to workshops on the following topics: “How organisations can use Internet tools and social media to enhance their offer and communicate with their members and broader audiences”, “How can organisations make healthy eating easy and enjoyable for people with RMDs”, “Youth workshop: From plan to action - taking the Youth Group strategy forward”, and “How to develop a successful communications strategy”. Sanja participated in workshops mainly focused on rehabilitation, both moderated by Frane Grubišić, Croatian host doctor: “How can organisations build a case for rehabilitations” and “Using recommendations to improve healthcare for people with RMD's at a national level”. Her interest was also in “Internet tools and social media” and “Communication strategy”.

We actively participated in the conference with Sanja's poster presentation: “INA connected us - Ongoing project of educating medical staff about Scleroderma” and by showing a promotional video on rare diseases made by Croatian Alliance for Rare Diseases.

During breaks and dinners we continued making friends and connections.

November 2014

Annelise Roennow (Danish Scleroderma & Raynaud's Association)

Sanja Roskar (Croatian Society for Patients with Scleroderma)

Questionnaires and Surveys - Why bother? A wake-up call for us all

As people with systemic sclerosis, we are often asked to respond to questionnaires and surveys, or to participate in research protocols including therapeutic trials. We often wonder why we should bother.

The Swiss, Belgian and French associations asked Professor Yannick Allanore, president of EUSTAR, why it is important to respond or participate.

EUSTAR aims to foster the awareness, understanding and research of scleroderma and its management throughout Europe.

EUSTAR, the official organization of European specialists of systemic scleroderma, aims to:

- Increase knowledge of scleroderma in the population and among physicians;
- Improve research on scleroderma that is patient-oriented;
- Improve support for people with scleroderma.

Professor Allanore, why is it important, as patients, to answer the surveys or questionnaires received regularly from referral centers or from our association?

This disease remains poorly understood in the general population and in the medical and health-professional arena. Information about systemic sclerosis is often limited because of the small numbers of participants in surveys, and so if we want to provide clear messages at all levels, to both patients and medical caregivers, precise and accurate information is needed. Another key point is the heterogeneity of the disease, because if one asks only a small group, the result is highly exposed to bias, depending on the sample interviewed.

To overcome these problems, we need to obtain information from a large number of patients. If necessary, we need to organise this information according to the duration of illness, age or other characteristics, but it is important to have as large a volume of information as possible. In current questionnaire or survey methods, there is a strong tendency to ask the opinion of patients, and after several years' analysis of laboratory tests and other complementary tests, many studies of "patient-reported outcomes" have now been conducted in rheumatology.

For clinical trials, how does a pharmaceutical- or European Union-funded study work?

Whoever the sponsor, they must create a protocol validated by experts in the field, obtain a favourable decision from an ethics committee, and plan a budget for setting up logistics (e.g. collection of books, internet tools, software, review centralization) and human resources (e.g. nurses, examiners). They then compensate hospitals for the incurred extra costs (e.g. use for the study of hospital resources). Patients are recruited, separated into the different areas of the study, ideally by a blind lottery, and then they are monitored closely to verify that the procedure does not create any risks (the patient is often even more closely monitored during routine care when he is participating in a clinical trial). Once the total number of required patients is reached, finalization of the parameters takes a good deal of time, and once all data are available, a statistical analysis is performed by an independent team to determine if the objectives have been met, and to communicate the results. All these essential steps explain why it takes so long to complete a therapeutic trial.

If you cannot conclude a study due to a lack of response, what happens?

If the desired number, which is usually pre-calculated with the help of prior studies, is not reached, the study will generally not give the answer to the question that is hoped for. In the case of a clinical

trial, all the work done may prove useless if the response is weak due to a lack of participants, and the result will be inconclusive, so that we cannot even answer the question, for example, about whether a given treatment is more effective than that with which it is being compared.

Can you tell us briefly about an important study called DeSSciper and about what will happen in three years if the study cannot be completed due to lack of data?

DeSSciper is a huge observational study, which means that it collects data from routine care of patients, following the standard monitoring proposed by each center without changing anything (no additional tests, no new drug trials). In fact, during this project we are looking for homogeneous groups of patients (for patients with high risk of pulmonary hypertension, for example), and after three years of study of such groups, we will be able to compare if the different treatment regimes have influenced their disease, for example by development of PAH.

This study also considers lung fibrosis, digital ulcers, arthritis, and heart involvement. So all of the major aspects of the disease will be covered. However, because we will focus on specific groups, if the number of patients is insufficient, the result will be approximate and we will not be able to reach a conclusion which could guide future management of the disease.

For some time now, pharmaceutical companies have shown interest in rare diseases, including scleroderma. What will happen if these pharmaceutical companies do not get results in the studies they are funding?

There is great interest in scleroderma because in rheumatology we have seen great progress with the advent of biotherapies that have changed the prognosis, for example, of rheumatoid arthritis. After having invested heavily in common diseases, the pharmaceutical industry is now interested in biotherapies for rare diseases, because it could be a new outlet for their molecules, and there are high expectations in this area.

Furthermore, because we understand and use these molecules in other cases, we have a good deal of confidence in their use in scleroderma. However, industry has also tried out their products in lupus for example, in studies that were difficult to achieve and to interpret. If we end up with the same result in scleroderma, getting poor participation in studies, or not identifying robust criteria for these studies, there is a risk that these companies may change their targets and move towards other inflammatory and autoimmune diseases.

If a person suffers from a severe but stable scleroderma, can s/he be part of a protocol for a drug test?

Each study has different inclusion and exclusion criteria according to its objectives. The study may be directed at finding an answer about the potential of a product to slow, stop, or prevent the development of skin fibrosis. In these different scenarios, patients will be recruited who are at different stages of the disease and who have had it for differing durations, so that there are therefore many possibilities for different manifestations of the disease. However, it should be noted that today the predominant strategy is to try to find products that can slow the progression and spread of skin fibrosis, which leads to the choice of diffuse cutaneous forms at an early stage. To find out if a patient can participate in a study, it is necessary to ask the principal investigator about the inclusion and exclusion criteria, and to analyze the situation of the patient. This can be done by asking our researchers, who are always available to explore the possibilities of recruiting patients.

We want to emphasise to all our readers that it's essential for us all that our doctors and pharmaceutical companies continue to be interested in our cause. Otherwise, in a very short time, we will not have any new drugs and no new research into better treatments. WE CAN DO MORE!



The DeSScIPHER Project

"To decipher the optimal management of Systemic Sclerosis"



Within this newsletter, we want to take the opportunity to thank you for your effort to support DeSScIPHER!

Since the start (almost two years ago) of the five observational trials, nearly 1700 patients with systemic sclerosis have been screened and more than 1500 patients have been enrolled into the trials.

Thus, with the help of FESCA and other contributing centers the DeSScIPHER project had become the largest prospective observational research project ever to take place on systemic sclerosis!

What is the DeSScIPHER project?

DeSScIPHER is the **1st international EC-funded research project**, and currently also the largest project, on the rare disease systemic sclerosis (SSc). DeSScIPHER aims to **decipher the optimal management of systemic sclerosis**. The goals of this project are to improve the treatment strategies for people with systemic sclerosis, and thus to help affected patients to get more quality of life.

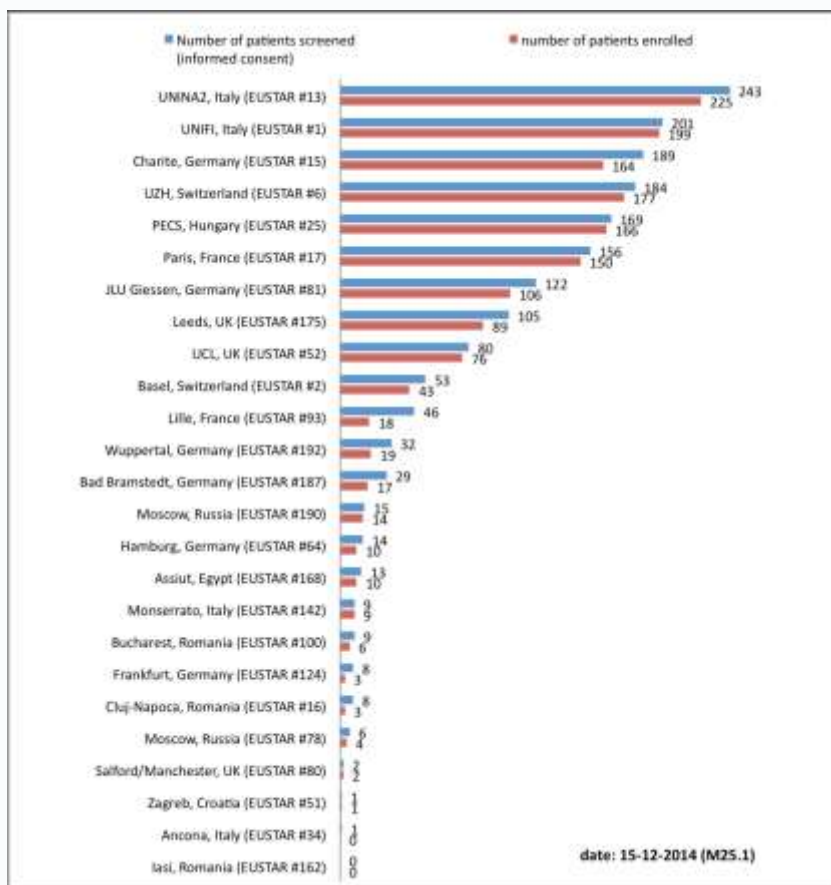
The projects comprises **five observational, non-interventional studies** which started in April 2013 and have been designed to cover different evolution phases of the disease from early, functionally relevant manifestations such as **digital ulcers** and **hand arthritis** to later, more severe organ manifestations such as **interstitial lung disease, pulmonary hypertension** and **severe heart disease**.

Moreover, DeSScIPHER aims to improve the **education** of people with systemic sclerosis and physicians, and ultimately to achieve a **better care for patients** by the development of accepted evidence-based clinical **guidelines**.

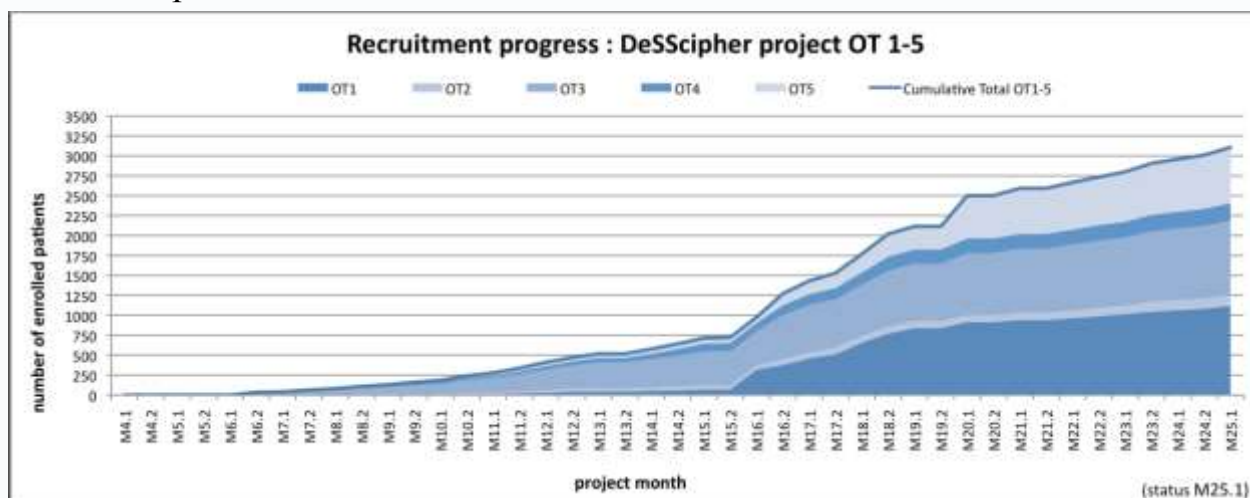
The activities of FESCA within the DeSScIPHER project

FESCA aisbl. is a full partner of the DeSScIPHER project and deeply involved since the very beginning of the five observational trials. The main task of FESCA is to actively disseminate the research project in Europe and in its member countries. To introduce the project the main launch activities were in 2013 but some member countries joined to communicate the project in 2014.

Please find the detailed patient recruitment numbers for each OT (observational trial) and the center on the following page:



Number of patients enrolled into the observational arms of all OTs:



Next steps

The project will be closed by the end of 2015. After the results are ready to distribute, it will be FESCA's task will be to help disseminate the outcome among our member countries in 2016.

Once again we thank you for the contribution of our member associations to help achieving this great number of participation.

Beata Garay Toth
Vice-president, FESCA
DeSSciper representative

World Scleroderma Day The Netherlands



In the context of World Scleroderma Day having approximately 20 people indulged on Saturday, June 21.

Upon entry everybody was welcomed with coffee, tea and a pastry. The location was in the middle of the Netherlands in Utrecht and very cozy and nice. After a presentation by dermatologist Renate Reinders about what a dermatologist can do for people with scleroderma, there was time to go practical to work.

Beside the dermatologist, there were visagists (make-up artists,) Silvia Koekkoek and Harriette Mooiweer to give everyone some practical tips. And some people were drawn with exclusive cream and they all received samples of this cream when they left.

The quests present were divided in three groups to give everyone optimal opportunity to receive personal tips and ask questions. All the people found the program and the seclusion of the group very valuable and positive.

In a casual atmosphere everybody really enjoyed this day. In addition this day revealed how nice it is to talk with other people who experience the same difficulties. Peers appeared to be the most important aspect this beautiful day!

Joep Welling, NVLE

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.

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International Non-Profit Association

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