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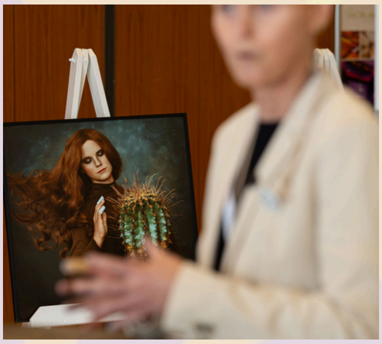
FESCA IVZW
Federation of European Scleroderma Associations

CONGRESS REPORT

8th Systemic Sclerosis Patient World Congress 2024

14-16th March, 2024, Prague, Czech Republic



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Message from Sue Farrington (FESCA President) and Ilaria Galetti (FESCA Vice-President and Chair of the Congress Organisation Working Group)

We are delighted to present this report from the 8th Systemic Sclerosis Patient World Congress, a hallmark event organised by the Federation of European Scleroderma Associations (FESCA), in partnership with the World Scleroderma Federation. This year's congress, which brought together scleroderma patients, caregivers, clinicians, and researchers from around the globe, was a remarkable testament to the strength and unity of our community.

The energy at the congress was palpable from the very beginning. Conversations buzzed with excitement and hope as members shared their experiences and exchanged ideas. It was heartening to witness the camaraderie and support that are the hallmarks of our community.

The programme of the congress offered insightful content that catered to the diverse interests of our attendees. The contributions from our speakers which included both patients and clinical experts were truly exceptional, covering a wide range of topics from the latest research breakthroughs to practical advice on managing daily life with systemic sclerosis. While designed by and for scleroderma patients, the programme also received overwhelmingly positive feedback from clinicians and nurses who appreciated the opportunity to gain deeper insights into the patient experience, which, in turn, will inform their clinical practices and enhance the care they provide.

A particularly memorable part of the congress was the stunning photo display organised by Michaela Linková from our Czech member organisation Revma Liga, which beautifully captured the faces and stories of those living with scleroderma. This exhibition was more than just a visual treat; it was a poignant reminder of the resilience and courage that define people living with the disease.

As this is a biannual event, we are already looking forward to the next Systemic Sclerosis Patient World Congress in 2026, which will be held in the vibrant city of Athens. We anticipate another exceptional gathering that will further our collective goals and strengthen our global community.

We take this opportunity to extend our gratitude to the World Scleroderma Federation for this fruitful collaboration and look forward to the continued partnership. The success of the congress would not have been possible without the exceptional efforts of our speakers and moderators, the organisation team, the event sponsors, and, most importantly, without the active participation of our incredible attendees. To all of you, we say a sincere thank you.

Warmest regards,

SFarrington

Sue Farrington
FESCA President

Ilaria Galletti

Ilaria Galetti
FESCA Vice-President and
Chair of the Congress
Organisation Working

About FESCA and the Systemic Sclerosis Patient World Congress

Federation of European Scleroderma Associations (FESCA) is an umbrella group of national scleroderma patient organisations with 28 members across Europe, dedicated to improving the standard of life and access to quality care for those living with systemic sclerosis (SSc). FESCA is proud to be the organiser of the biannual Systemic Sclerosis Patient World Congress designed by patients and for patients.

Our congress aims to educate and empower patients and the SSc community, reflecting FESCA’s commitment to patient and public education as a core strategic pillar. Following the virtual format of the last two congresses due to the COVID-19 pandemic, this year’s event returned to an in-person gathering in Prague, Czech Republic on 14-16 March. Held alongside the medical congress organised by the World Scleroderma Foundation, the event fostered a collaborative environment between patients and healthcare professionals, enhancing mutual understanding and support.

Programme and session summaries

The programme of the 8th Systemic Sclerosis Patients World Congress in Prague uniquely featured scleroderma patients as speakers and moderators, sharing the stage with world-renowned expert healthcare professional (HCPs) in the field. It aimed to provide an informative and accessible exchange of knowledge, with sessions tailored for a lay audience. Among other topics, the content covered the latest research, treatment options, and personal experiences, ensuring that attendees gain valuable insights, empowering them in their own scleroderma journey.

Aside from the exciting patient programme, all attendees were invited to the official opening of the medical congress in the evening of 14th March. Moreover, representatives of FESCA member associations attended the FESCA Members Meeting earlier that day, networking and brainstorming about the unmet needs and challenges of scleroderma patients which FESCA could tackle in its advocacy work.

For those who were not able to attend, the content of the sessions was summarised below. In addition to the summaries, some of the congress sessions were recorded and can be accessed through the links below in several languages:

English Czech Spanish Hungarian German

FRIDAY, MARCH 15

TIME	PANORAMA HALL	CLUB ROOM B	CLUB ROOM C	CLUB ROOM D
9:00 9:30	**OPENING SESSION** **Speakers:** Sue Farrington (UK), Václav Pláteník (CZ), Michaela Linková (CZ), Marco Matucci-Cernic (IT)			
9:30 10:30	**DECODING DRUG DEVELOPMENT: PATIENT ORGANISATION ENGAGEMENT ACROSS THE DRUG LIFECYCLE** **Moderator:** Ilaria Galetti **Speakers:** Annie Gilbert (UK), Michael Oeschger (DE), Kristina Davidson (USA)			
10:30 - 11:00 COFFEE BREAK				
11:00 12:00	**WHAT'S NEW IN ILDs?** **Moderators:** Katerina Antoniou (GR) & Edith Brown (UK) **Speakers:** Michael Oeschger (DE), Monique Hinchcliff (USA), Elisabetta Renzoni (UK)	**SYSTEMIC SCLEROSIS: ONE OR MANY DISEASES?** **Moderator:** Sue Farrington (UK) **Speakers:** Michaela Linková (CZ), James Seibold (USA), Silvia Bellando Randone (IT)	**WHAT'S NEW IN PULMONARY ARTERIAL HYPERTENSION?** **Moderator:** Monica Holmner (SE) **Speakers:** Yannick Allanore (FR), Pavel Jansa (CZ), Annelise Rønnow (DK)	**GROWING UP WITH SSC: NAVIGATING THE TRANSITION TO ADULTHOOD** **Moderators:** Linda Schraven (NL), Kim Fligelstone (UK) **Speakers:** Ivan Foeldvari (DE), Catarina Leite (PT), Teresa Pizzetti (IT)
12:00 - 13:00 LUNCH				
13:00 14:00	**MIND MATTERS: TACKLING MENTAL HEALTH IN SSc JOURNEY** **Moderator:** Rita Schriemer (NL) **Speakers:** Linda Kwakkenbos (NL), Steffi Säurig (DE), Francesca Ingegnoli (IT)	**BUMP AND BEYOND: NAVIGATING PREGNANCY WITH SSc** **Moderator:** Ilaria Galetti (IT) **Speakers:** Maria-Grazia Lazzaroni (IT), Catarina Leite (PT)	**FACING SSc TOGETHER: EXPLORING QoL IN MEN WITH SSc** **Moderator:** Michael Oeschger (DE) **Speakers:** Alain Lescoat (FR), Stephan Houbertz (DE)	**HANDY SOLUTIONS: DEALING WITH HAND CHANGES IN SSc** **Moderators:** Beata Garay (HU), Gabriella Nagy (HU) **Speakers:** Alison Zheng (CN), Marco Matucci-Cerinic (IT), Khadija El Aoufy (IT)
14:00 - 14:15 BREAK				
14:15 15:45	**CLINICAL PRACTICE GUIDELINES AND RECOMMENDATIONS: WHAT THEY ARE AND WHY WE NEED THEM** **Moderators:** Kim Fligelstone (UK), Monica Holmner (SE) **Speakers:** Anna-Maria Hoffman-Vold (NO), Carina Boström (SE)			
16:00 17:00		**THE EFFECTS OF STRESS IN AUTOIMMUNITY - Czech language only** **Moderator:** Michaela Linková (CZ) **Speaker:** Monika Cervinková (CZ)		

SATURDAY, MARCH 16

TIME	PANORAMA HALL	CLUB ROOM B	CLUB ROOM C	CLUB ROOM D
10:00 - 10:15 BREAK				
10:15 11:15	**FATIGUE, INVISIBLE BUT HEAVY** **Moderators:** Monica Holmner (SE), Janet Poole (USA) **Speakers**: Janet Pope (USA), Rong Mu (CN), Annelise Rønnow (DK)	**TRANSPLANTS IN SYSTEMIC SCLEROSIS** **Moderators:** Ann Kennedy (IE), Doron Rimar (IL) **Speakers:** Elana Bernstein (USA), Julia Spierings (NL), Michael Oeschger (DE), Silvia Sandulescu (ROU)	**SCLERO-ID AND ITS IMPORTANCE FOR SSc PATIENTS AND IN CLINICAL TRIALS** **Moderators:** Beata Garay (HU), Cosimo Bruni (IT, CH) **Speakers:** Rucsandra Dobrota (CH), Oliver Distler (CH)	**WHY DO WE KEEP ON SUPPRESSING THE IMMUNE SYSTEM?** **Moderators:** Edith Brown (UK), Swantje Arndst (DE) **Speakers:** Sabina Oreska (CZ), Jörg Distler (DE)
11:15 - 12:00 BRUNCH				
12:00 13:00	**GET MOVING: RECLAIMING WHAT SYSTEMIC SCLEROSIS TOOK AWAY** **Moderator:** Linda Schraven (NL) **Speakers:** Janet Poole (USA), Rubén Duarte Fernandes (UK), Tânia Santiago (PT)	**HOW TO SEE THE BODY THROUGH VIDEOCAPILLAROSCOPY ?** **Moderators:** Maurizio Cutolo (IT), Michael Oeschger (DE) **Speakers:** John Pauling (UK), Vanessa Smith (BE)	**LIFE HACKS: NAVIGATING EVERYDAY WINS WITH SSc** **Speakers:** Annelise Rønnow (DK), Monica Holmner (SE)	**HOW SHOULD DOCTORS TELL THEIR PATIENTS “YOU HAVE SYSTEMIC SCLEROSIS”?** **Moderators:** Steffi Säurig (DE), Czirjak László (HU) **Speakers:** Kim Fligelstone (UK), Masataka Kuwana (JP), Michael Hughes (UK)
13:00 - 13:15 BREAK				
13:15 14:00	**BREAKING GROUND: EXPLORING THE LATEST FRONTIERS IN SSc RESEARCH** **Moderator:** Sue Farrington (UK) **Speakers:** Christopher Denton (UK), Marco Matucci-Cerinic (IT), Christina Bergmann (DE)			
14:00 14:30	**CLOSING SESSION** **Speakers:** Maureen D. Mayes (USA), Michaela Linková (CZ), Ilaria Galetti (IT)			
14:30 - 15:30 FAREWELL DRINK				

Patient Congress Opening Session

Speakers: Sue Farrington (President of FESCA, Chief Executive at SRUK, United Kingdom), Václav Pláteník (Deputy Minister of Health, Czech Republic), Michaela Linková (SSc Patient, Leader of Revma Liga, Czech Republic), Marco Matucci Cerinic (Professor of Rheumatology at University Vita-Salute San Raffaele, President of the World Scleroderma Foundation, Italy)

Sue Farrington welcomed attendees and expressed delight at finally meeting in person. She emphasised the importance of collaboration between patients, clinicians, researchers, and industry for better treatment access. Václav Pláteník spoke about the Czech Republic's efforts to support patients with rare diseases, emphasising their integration into European reference networks and ongoing projects to improve access to healthcare and social services. Michaela Linková shared some of the challenges patients face, including delayed diagnosis, lack of psychological support, and integration into the workforce. She emphasised the role of patient organisations in support and advocacy. Lastly, Professor Marco Matucci Cerinic reflected on his journey into studying scleroderma. He highlighted the importance of patient input in understanding and treating diseases, expressing gratitude for collaboration with FESCA.

> “*This is a teaching that I give to my students: always listen, because you study, you listen to professors but then you if you really want to understand, you must listen to the patient.*”

Decoding Drug Development: Patient Organisation Engagement Across the Drug Lifecycle

Moderator: Ilaria Galetti (SSc Patient, Vice-President of FESCA, Italy)

Speakers: Annie Gilbert (Global Patient and Site Engagement Lead, Boehringer Ingelheim, United Kingdom), Kristina Davidson (Senior Director of Patient Advocacy, Amgen, USA), Michael Oeschger (SSc Patient, German Scleroderma Association, Germany)

The discussion emphasised the crucial role of actively engaging patients throughout the drug development lifecycle, despite existing challenges, particularly regarding timing. Annie Gilbert underscored the necessity of integrating patient perspectives into drug development processes, while highlighting the ongoing challenges.

Kristina Davidson also emphasized the early involvement of patients in research, with speakers concurring on the benefits, including understanding unmet needs, improving compliant protocols, reducing drop-off rates, and better identifying potential patient benefits. Additionally, Annie Gilbert stressed the importance of front-loading activities, such as developing evidence plans and ensuring diversity, equity and inclusion in clinical trials.

Moreover, the discussion addressed other challenges, especially in terms of timing and the persistent difficulty in contracting, despite having robust legal and compliance frameworks, with contracts still taking up to eight weeks. The speakers also delved into the significance of measuring patient engagement, emphasising the need for tangible evidence of success beyond mere discussion.

> *Early involvement of patients allows for a better understanding of the disease. Patients with rare diseases often have years sometimes even decades of experience with their diseases and they can provide valuable insights about their symptoms.*

What's new in Interstitial Lung Diseases?

Moderators: Katerina Antoniou (Professor of Respiratory Medicine at Medical University of Crete, Greece,) & Edith Brown (SSc Patient, SRUK, United Kingdom)

Speakers: Michael Oeschger (SSc Patient, German Scleroderma Association, Germany), Monique Hinchcliff (Associate Professor of Medicine at the Yale School of Medicine, USA), Elisabetta Renzoni (Consultant Respiratory Physician at Royal Brompton Hospital, United Kingdom)

The session addressed the challenges and complexities of SSc-associated interstitial lung disease (SSc ILD). Edith Brown and Michael Oeschger shared personal experiences and Michael discussed the three phases of unmet needs: pre-diagnosis, diagnostic phase, and post-diagnostic phase, emphasising the need for improved awareness among healthcare professionals and patients. He also emphasised the need for multidisciplinary approaches and national guidelines to improve diagnosis and treatment during the diagnostic phase and regretted the lack of curative treatments and specialised support for patients and caregivers after diagnosis.

Monique Hinchcliffe discussed recent research on the pathogenesis of SSc ILD, focusing on gene expression and epithelial mesenchymal transition (EMT). She acknowledged the complexity of the topic but expressed hope for advancements in precision medicine for patients with scleroderma-related lung complications. Finally, Elisabetta Renzoni provided clinical insights into SSc ILD, highlighting its variability, diagnostic methods, treatment options, and the importance of multidisciplinary care. The session underscored the urgent need for advancements in understanding, diagnosis, and treatment of SSc ILD to improve patient outcomes.

> “*Early diagnosis enables the early use of current treatment options and can prevent damage. It also enables better monitoring of disease progression.*

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> *Multidisciplinary care is essential. We need psychological support for patients much more than we have right now. We need every patient to have access to pulmonary rehabilitation, supplemental oxygen, symptom control, palliative care and of course, disease modifying drugs.*”

Systemic Sclerosis: one or many diseases?

Moderator: Sue Farrington (President of FESCA, Chief Executive at SRUK, United Kingdom)

Speakers: Michaela Linková (SSc Patient, Leader of Revma Liga, Czech Republic), James Seibold (Rheumatologist, President of Scleroderma Research Consultants, USA), Silvia Bellando Randone (Associate Professor of Rheumatology at the University of Florence, Italy)

Michaela Linková shared the challenges she faced as an SSc patient. Dealing with a rare disease diagnosis was full of uncertainty, fear and lack of understanding. She highlighted the significance of patient education and empowerment, encouraging individuals to take an active role in their healthcare and communicate effectively with medical professionals. She also emphasised the importance of seeking support from various sources, including patient organisations and psychologists, to address the mental health aspect of dealing with the illness.

Prof James Seibold provided insight into managing the complexity of SSc and presented its diverse manifestations and impacts. SSc can affect many different body areas, from skin, fingers or legs to organs. While the exact cause of SSc is unknown for most of the patients, factors such as environmental exposures, e.g., silica dust, and genetic predispositions are implicated.

Lastly, Prof Syliva Bellando discussed the diverse nature of SSc, emphasising its complexity and varied manifestations. She highlighted some prevention and management strategies, such as a healthy diet, exercise, avoiding smoking or controlling hypertension. Following these tips can help mitigate risks and improve outcomes. The emotional toll of SSc, including depression and anxiety, underscores the need for a multidisciplinary approach.

> *There are so many elements in the SSc as genetics, etc. We don’t know the exact mechanism of how SSc is born.*
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> *Mental health should be a part of the treatment as it affects this disease a lot.*
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> *People who have a stable state of the disease experience less mortality than the ones where the illness is still changing its state.*

What's new in Pulmonary Arterial Hypertension?

Moderator: Monica Holmner (Vice-Chair of the Swedish Rheumatism Association for SSc and FESCA Board member, Sweden)

Speakers: Yannick Allanore (Professor of Rheumatology at Cochin Hospital, France), Pavel Jansa (Head of PH Centre at General University Hospital in Prague, Czech Republic,), Annelise Roennow (SSc Patient, FESCA Communications Manager, Denmark)

This session focused on new developments in pulmonary arterial hypertension (PAH), including available treatments, early signs and symptoms, and the patient's experience.

The speakers discussed the importance of diagnosis and distinguishing between different types of PH when it comes to prescribing appropriate treatment. The main tests for defining PH type include echocardiography and pulmonary function tests.

Identifying the type of PH in SSc patients poses a particular challenge for doctors. Multidisciplinary team discussions are essential to determine the appropriate treatment strategy. Additionally, regular screening should be offered annually to detect PH early. Careful follow-up and monitoring are crucial for disease control and treatment efficacy assessment.

Lastly, it was noted that mental health considerations are paramount in addressing the psychological impact of illness on patients and their caregivers. Moreover, there is a consensus on the importance of physical activity, particularly walking, in enhancing patients' overall quality of life and prognosis.

> *Regular screening should be offered to all patients systematically and at least annually.*

Growing Up with Systemic Sclerosis: Navigating the Transition to Adulthood

Moderators: Linda Schraven (SSc Patient, FESCA Secretary, Netherlands), Kim Fligelstone (SSc Patient, FESCA Advisory Board Member, United Kingdom)

Speakers: Ivan Foeldvari (Paediatric Rheumatologist, Hamburg Centre for Pediatric and Adolescence Rheumatology, Germany), Catarina Leite (SSc Patient, Psychologist and President of the Portuguese Association of Patients with Scleroderma, Portugal), Teresa Pizzetti (Associazione Italiana Lotta alla Sclerodermia (AILS), Italy)

The session focused on the challenges faced by young individuals with SSc, particularly regarding stigma and emotional understanding. Ivan Foeldvari emphasised the importance of delicately explaining the condition to children without overwhelming them with technicalities or drama, allowing them to maintain their innocence and childhood despite their illness. Additionally, the importance of children understanding their condition was underscored for easier adherence to treatment.

Catarina Leite shared her personal journey with juvenile scleroderma, highlighting how her parents prioritised her normal childhood and how she maintained a fulfilling life despite the limitations imposed by her condition. She emphasised the importance of not overprotecting children with scleroderma and allowing them to live as normally as possible to preserve their self-esteem.

Teresa Pizzetti, a mother of a child with scleroderma, discussed her daughter's treatment journey, highlighting the challenges of transitioning from paediatric to adult care and advocating for improved communication between medical professionals.

> *Parents will always be scared.*
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> *Doctors need to know how to speak to children about the disease, without interrupting their childhood or giving them extra unnecessary fears.*
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> *Children deserve a normal life despite their condition.*

Mind Matters: Tackling Mental Health in the SSc Journey

Moderators: Rita Schriemer (Patient Engagement Coordinator, Sint Maartenskliniek, Netherlands)

Speakers: Linda Kwakkenbos (Assistant Professor at the Department of Clinical Psychology, Behavioural Science Institute, Radboud University Nijmegen, Netherlands), Steffi Säurig (SSc Patient, Scleroderma Liga e.V., Germany), Francesca Ingegnoli (Rheumatologist at the Gaetano Pini Hospital in Milan, Italy)

Linda Kwakkenbos, Co-Director of Scleroderma Patient-centered Intervention Network (SPIN), discussed a person-centered approach to coping with scleroderma, promoting positive health and self-management. SPIN focuses on identifying patient needs and developing programs like Spin chat COVID-19 home isolation activities to empower those with scleroderma. Steffi Säurig shared her personal experience with scleroderma as well as her coping strategies, emphasising information gathering, support seeking, and life adjustments. Francesca Ingegnoli highlighted mental health burdens in rheumatic diseases, urging better communication between patients and clinicians to address these issues. The session emphasised proactive mental health management in chronic illness and encouraged open dialogue between patients and healthcare providers.

> *Positive health is defined as the ability to adapt and to self-manage. Which basically means that there are things that you can do yourself to adapt to the disease, to self-manage your disease and to feel healthier again.*

Bump and Beyond: Navigating Pregnancy with Systemic Sclerosis

Moderator: Ilaria Galetti (Vice-President of FESCA, Italy)

Speakers: Maria-Grazia Lazzaroni (Rheumatologist at the University Hospital of Brescia, Italy), Catarina Leite (SSc Patient, Psychologist and President of the Portuguese Association of Patients with Scleroderma, Portugal)

The session covered various aspects of SSc and pregnancy, highlighting the complexities and challenges faced by patients.

Maria-Grazia Lazzaroni stressed the advancements in understanding and managing SSc during pregnancy over the last two decades, with more frequent pregnancies observed among SSc patients. Concerns regarding pre-term delivery, caesarean sections, and medication safety persist. However, there are now safe treatments that can be used during pregnancy. Planning is emphasised as crucial for SSc patients considering pregnancy, requiring a multidisciplinary approach involving rheumatologists and obstetricians. Lazzaroni also presented the results of a study that examined patient perspectives, revealing desires for pregnancy among many SSc patients. The study also showed that the long-term neurodevelopmental prognosis for children born to mothers with SSc is reassuring, showing no distinct pattern of neurological disorders.

Catarina Leite shared her pregnancy journey as a SSc patient and she discussed the challenges she faced after childbirth, mainly the physical limitations and lack of strength but highlighted her son's understanding and adaptability to her needs.

The session concluded underscoring the need for ongoing research and multidisciplinary collaboration to enhance outcomes for SSc patients planning or experiencing pregnancy. The speakers also highlighted the importance of improved communication between medical professionals and the support networks for SSc patients during the pregnancy journey but also for those who are not able to become a mother.

> *Currently there are no guidelines for pregnancy in SSc; because the disease is rare and pregnancy is rarer.*
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> *52% of the SSc patients under 45 years old desired a pregnancy.*
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> *The difficult part is the lack of the strength to grab the baby; I could only do it while I was sitting.*

Facing SSc Together: Exploring Quality of Life in Men with Systemic Sclerosis

Moderator: Michael Oeschger (SSc Patient, German Scleroderma Association, Germany)

Speakers: Alain Lescoat (Doctor of Medicine, Head of the Scleroderma Program at Rennes University, France)

Dr Alain Lescoat, who has been specialising in SSc for over a decade, focused on its impact on quality of life and occupational exposure, such as silica affecting men with Scleroderma. Lescoat emphasised the severity of SSc in men and the importance of patient voices in discussions about the disease. He provided an overview of the epidemiology, noting that the disease is more common in women but tends to be more severe in men, particularly with manifestations like diffuse cutaneous involvement and ILDs.

He discussed the specific experiences of men with SSc, drawing on recent literature and focus groups. Key themes included the impact on masculinity, challenges in coping, and the need for support. Men reported that the disease affected their roles and activities, their ability to work, and their sexual health, including erectile dysfunction.

> *Men constitute around 17% of systemic sclerosis patients.*
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> *Some men highlighted that they had to renounce to some of what defined them as men due to SSc.*
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> *Men living with SSc ask for different support than women.*

Handy Solutions: Dealing with Hand Changes in SSc

Moderators: Beata Garay (SSc Patient, FESCA Advisory Board member, Hungary), Gabriella Nagy (Assistant Professor, Department of Rheumatology and Immunology, University of Pecs Medical School, Hungary)

Speakers: Alison Zheng (SSc Patient, Founder and President of the Chinese Organization for Scleroderma, China), Marco Matucci Cerinic (Professor of Rheumatology at University Vita-Salute San Raffaele, President of the World Scleroderma Foundation, Italy), Khadija El Aoufy (Research Fellow at the Department of Experimental and Clinical Medicine, University of Florence, Italy)

The session focused on methods and treatments used for patients with Raynaud’s, ulcerated hands and calcinosis, as well as practical self-management.

Alison Zheng shared her personal experience detailing the challenges she faced with finger problems exacerbated during winters, leading to intense pain and hand. Despite these struggles, she remains hopeful, advocating for others to learn from her experience to prevent unnecessary pain.

Marco Matucci emphasised the criticality of hand care for SSc patients, outlining the progression of hand symptoms and emphasising the importance of prompt treatment to prevent disease evolution. He stressed patient education, underscoring the role of nurses in treatment and highlighting the necessity of hand protection and early rehabilitation. Khadija El Aoufy elaborated on management strategies, recommending exercises, addressing emotional triggers, and advocating for adherence to treatment protocols and good hygiene practices. The session underscored the importance of patient empowerment, emotional awareness, lifestyle modifications, and telemedicine in SSc management.

> “*Physiotherapy to treat hand problems gives good results, it maintains hand function in time.*

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> *Monitoring pain is key so the professionals can help choose the best treatment.*”

Clinical Practice Guidelines and Recommendations: what they are and why we need them

Moderators: Kim Fligelstone (SSc Patient, FESCA Advisory Board member, United Kingdom) and Monica Holmner (Vice-Chair of the Swedish Rheumatism Association for SSc and FESCA Board member, Sweden)

Speakers: Anna-Maria Hoffman-Vold (Senior Consultant in Rheumatology, Oslo University Hospital, Sweden), Carina Boström (Associate Professor at Karolinska Institutet, Sweden)

The session emphasised the importance of clinical practice guidelines in providing structured care for patients, likening them to a GPS navigation system for both patients and healthcare providers. Dr Hoffman stressed the necessity of evidence-based guidelines, detailing the development process for guidelines on ILDs in SSc.

Despite challenges such as expanded research questions causing delays, the team remained dedicated to ensuring the quality and relevance of the guidelines. She also outlined the forthcoming topics covered by the guidelines, including screening, diagnosis, monitoring, and treatment strategies for SSc-ILD.

Karina Boström presented recommendations for non-pharmacological management of SSc, highlighting a multidisciplinary approach and key recommendations such as tailoring management to individual needs and incorporating patient education.

Future research directions and plans for disseminating and implementing the guidelines were discussed, emphasising collaboration with patient organisations and healthcare professionals.

> *We need these clinical practice guidelines to develop a really structured path for the patients. They are always based on evidence.*

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> *Non-pharmacological treatments should not substitute for pharmacological treatment when the latter is required, and it should be directed towards improving health-related quality of life.*

The effect of stress on autoimmunity

Moderator: Michaela Linková (SSc Patient, Leader of Revma Liga, Czech Republic)

Speaker: Monika Cervinková (Doctor of Psychology, Support in autoimmune diseases, Czech Republic)

The session underscored the need for holistic approaches to managing stress and its effects on autoimmune conditions, emphasising the importance of psychological support in improving overall well-being.

Dr Červinková elaborated on the interconnectedness of biological systems, underlining the impact of stress on physical health, including symptoms such as joint pain, immune system impairment, and hormonal imbalances. She also discussed the interconnectedness of thoughts, behaviours, and emotions in managing stress and autoimmune diseases like scleroderma.

The session emphasised the importance of individualised approaches in finding what works best for each person. Techniques such as progressive muscle relaxation, visualisation, meditation, and hypnosis are discussed as tools for stress reduction and coping.

Recognising the thin line between positive and negative stress, with feedback from others is often crucial in identifying when stress becomes unhealthy. Participants shared personal experiences, highlighting the impact of stress on their lives and the need to respect the body's signals.

> *We cannot influence or change our emotions, but we can change our thinking and our behaviour.*
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> *Autoimmune diseases tend to break out especially in stressful phases of life.*

Gut Check: The Intestinal Tract and Microbiome in Systemic Sclerosis

Moderators: Elizabeth Volkmann (Rheumatologist, Director of UCLA Scleroderma Program, University of California, Los Angeles, USA), Catarina Leite (SSc Patient, Psychologist and President of the Portuguese Association of Patients with Scleroderma, Portugal)

Speakers: Ilaria Galetti (Vice-President of FESCA, Italy), Dinesh Khanna (Professor of Internal Medicine, University of Michigan, USA), Chiara Bellocchi (Doctor in Immunology and Allergology at Policlinico Hospital in Milan, Italy), Elizabeth Volkmann

Speakers discussed gastrointestinal (GI) issues in SSc patients, with a focus on symptom management and potential interventions. Ilaria Galetti provided an overview of the wide-ranging GI symptoms experienced by SSc patients, emphasising their impact on daily life. She also discussed differential diagnosis and non-pharmacological management of GI symptoms. Dr Khanna stressed the importance of effective communication between patients and healthcare providers regarding GI symptoms and introduced the UCLA SCTC GIT questionnaire for assessing these symptoms comprehensively.

Dr Khanna further explored treatment options for constipation and bacterial overgrowth, emphasising the need for individualised therapy. Dr Chiara Bellocchi discussed the role of gut microbiota in autoimmune diseases like SSc and the potential benefits of probiotics in managing GI symptoms, albeit with variations in efficacy across conditions.

The discussion also touched upon faecal microbial transplantation (FMT) as a potential therapeutic approach, stressing the need for further research to establish its safety and efficacy in SSc. Elizabeth Volkman underscored the importance of mindful eating and maintaining a food diary to understand the impact of dietary choices on symptoms.

> *You have to go to the dentist; it is painful because you have to keep your mouth open for a long time and not all dentists are trained to work with a scleroderma mouth.*

> *We have to change habits because we can’t eat the food we would like to eat.*

> *We are more worried about lungs and pulmonary hypertension because they are the leading cause of death. But your symptoms matter.*

> *The best way to start this journey with nutrition is to really go inward and try to make these connections between specific foods and how you feel.*

Fatigue, invisible but heavy

Moderators: Monica Holmner (Vice-Chair of the Swedish Rheumatism Association for SSc and FESCA Foard member, Sweden), Janet Poole (Professor and Program Director, Occupational Therapy Program at University of New Mexico, Albuquerque, USA)

Speakers: Janet Pope (Professor of Medicine in the Division of Rheumatology at the University of Western Ontario, Canada) Mu Rong (Professor and Director of the Department of Rheumatology and Immunology, Peking University, China), Annelise Rønnow (SSc Patient, FESCA Communications Manager, Denmark)

The session provided a comprehensive exploration of the challenges and management strategies associated with this complex symptom. Dr Janet Pope discussed the difficulties in accurately measuring fatigue and proposed non-pharmacological interventions like exercise while presenting data on its diverse underlying causes such as anaemia and depression. She also discussed her research on high-dose vitamin D supplementation as a potential treatment avenue. Dr Mu Rong further emphasised the intricate nature of fatigue, its profound impact on patients' quality of life, and the need for ongoing research to identify effective interventions.

Personal experiences shared by Annelise Roennow underscored the importance of listening to one's body and adopting a holistic approach to managing fatigue, encompassing lifestyle adjustments, medication adherence, and mindfulness techniques. Despite the absence of a universal remedy, strategies such as addressing inflammation and minimising long-term steroid use were highlighted as beneficial in alleviating fatigue symptoms. The session concluded with a call for continued research efforts aimed at unravelling the underlying mechanisms of fatigue in SSc patients and developing personalised treatment approaches to enhance patient well-being.

> “*Fatigue is very common and moderately severe in a lot of people you can see it's correlated with sleep.*
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> *Fatigue is quite complicated because symptoms result from different pathogenesis.*
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> *The most important thing is that it's okay to say no.*”

Transplants in Systemic Sclerosis

Moderators: Ann Tyrrell Kennedy (FESCA Advisory Board member, Ireland) Doron Rimar (Professor of Rheumatology and Director of Systemic Sclerosis Clinic Bnai-Zion Medical Center, Israel)

Speakers: Elana Bernstein (Director of Columbia University/NewYork-Presbyterian Scleroderma Center, USA), Julia Spierings (Rheumatologist, University Medical Centre Utrecht, Netherlands), Michael Oeschger (SSc Patient, German Scleroderma Association, Germany) Silvia Sandulescu (SSc Patient, President of Romanian Scleroderma Association, Romania)

The session explained what transplants are available for systemic sclerosis patients and any risks and benefits they might bring.

Elana Bernstein explained that lung, kidney and heart are the most common transplants in SSc, with reasons including ILD and PAH for lung, while kidney transplants often address scleroderma renal crisis, and heart transplants address myocardial fibrosis. Kidney transplants significantly improve survival rates compared to dialysis, while lung transplant survival rates vary depending on factors like disease subtype.

Julia Spierings focused on stem cell transplant and how this is being explored as a treatment option, offering benefits such as immune system reset, but also carrying risks like severe side effects. Spierings highlighted the importance of the selection of appropriate candidates and consideration of risks.

Michael Oeschger shared his own experience of undergoing a heart transplant due to heart fibrosis, which has granted him 14 years of new life. He emphasised that organ transplantation is a last resort but offers a definitive and effective solution. Living with a new heart means following some strict guidelines to maintain health, including avoiding infections, adhering to medication schedules, and adopting a healthy diet. He also acknowledged the responsibility that comes with being a transplant recipient.

Lastly, Silvia Sandulescu shared her journey of receiving a kidney transplant. She received the new organ during the COVID-19 pandemic, which liberated her from the need for thrice-weekly dialysis treatments. Now, four years post-transplant, she only requires regular check-ups and periodic blood tests. Grateful for the new life provided by her transplant, she cherishes each day with gratitude.

> “*With any solid organ transplant there are always risks.*
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> *Patients have to make clear decisions with their doctors. Peer support is also essential.*
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> *Receiving a new organ means a completely new mindset and a new life you will have to navigate.*
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>
> *Do’s after a transplant: be careful, grateful, and enjoy your life.*
> *A new heart is a new opportunity to fulfil all your dreams but also a responsibility for the receiver.*”

Sclero-ID and its importance for SSc patients and clinical trials

Moderators: Beata Garay (SSc Patient, FESCA Advisory Board member, Hungary), Cosimo Bruni (Rheumatologist, Department of Experimental and Clinical Medicine, University of Florence, Italy).

Speakers: Rucsandra Dobrota (Attending Physician, Department of Rheumatology, University of Zurich, Switzerland), Oliver Distler (Professor of Rheumatology and Chairman of the Department of Rheumatology at the University of Zurich, Switzerland)

The session delved into the significance of SCLERO-ID (Scleroderma Impact of Disease); a groundbreaking questionnaire crafted with the invaluable input of Systemic Sclerosis (SSc) patients worldwide.

Developed to aid in the assessment and qualification of symptoms in SSc patients, SCLERO-ID emerged as an international project endorsed by EULAR (European League Against Rheumatism). Rooted in a collaborative effort, the initiative commenced in 2015. Through a comprehensive cohort study involving 472 participants, SCLERO-ID meticulously evaluates the spectrum of symptoms across various manifestations of scleroderma.

The speakers highlighted some of the key aspects of this tool, such as its thorough coverage of essential health dimensions, the prioritisation of these dimensions based on patient rankings, and the rigorous weighting and validation processes undertaken. Crucially, patient involvement has been central to its evolution. As a Patient-Reported Outcome Measurement (PROM) tool tailored specifically for SSc, SCLERO-ID boasts remarkable feasibility, with 98% completion rate observed among respondents. Its availability in multiple languages signifies its potential for widespread utilisation.

> *SCLERO-ID helps to rate and qualify the symptoms in a SSc patient, and it is available in several languages.*
>
> ◆
>
> *Patient involvement has been central to its development.*

Why do we keep on suppressing the immune system?

Moderators: Edith Brown (SSc Patient, SRUK, United Kingdom), Swantje Arndt (SSc Patient, German Scleroderma Association, Germany)

Speakers: Sabina Oreska (Researcher at the Department of Rheumatology at Charles University in Prague, Czech Republic), Jörg Distler (Director of the Department of Rheumatology at the Hiller Research Center, University of Düsseldorf, Germany)

The session discussed the role of immunosuppressants in treating SSc, the benefits of using them, why results may vary and when they are best used.

Sabina Oreska provided insights into pharmaceutical treatments for SSc, discussing immunosuppressive drugs and various rheumatological options available. She discussed the need for personalised treatment plans due to potential reactions or side effects, highlighting the importance of close monitoring by experts and patient self-awareness.

She detailed different therapies based on disease severity, including the use of glucocorticoids, while also cautioning about the risks associated with certain treatments such as Autologous Hematopoietic Stem Cell Transplantation (AHSCT), which carries a high risk of mortality.

Jörg Distler highlighted the misconception of solely treating SSc as an inflammatory condition and stressed the importance of understanding its broader impacts throughout an individual's life. He advocated for a holistic approach that goes beyond targeting inflammation alone, acknowledging the effectiveness of current therapies while urging for a more nuanced perspective on SSc treatment strategies.

> *Since SSC is not a typical inflammatory disease, it is important to approach it according to its effects in the body through an individual’s life.*

◆

> *Immunosuppressive therapy helps to prevent or slow down the disease progression, but it should be tracked in detail by the expert.*

Get Moving: Reclaiming What Systemic Sclerosis Took Away

Moderator: Linda Schraven (SSc Patient, FESCA Secretary, Netherlands)

Speakers: Janet Poole (Professor and Program Director, Occupational Therapy Program at University of New Mexico, Albuquerque USA), Rubén Duarte Fernandes (Specialist Nurse in Rehabilitation, Centro Hospitalar e Universitário de Coimbra, Portugal) and Tania Santiago (Rheumatologist at Centro Hospitalar e Universitario de Coimbra, Portugal)

The session focused on managing SSc through physical activity and exercise, highlighting the benefits for symptoms and overall well-being. She outlined various exercises, including aerobic, resistive, and stretching, and stressed the importance of incorporating physical activity into daily routines. Reuben Duarte Fernandes, a specialist nurse, introduced the "I Fitness Project," a web-based program aimed at educating patients on lifestyle behaviours, focusing on physical activity. The project offers telehealth access to specialists and modules covering stretching, strength, resistance, and aerobic exercises. Both speakers underscored the significance of physical activity in systemic sclerosis management and provided practical tips and resources for integrating exercise into daily life.

Additionally, Tania Santiago discussed skin rehabilitation's importance, point out its impact on functionality and quality of life. She highlighted the need for comprehensive outcome measures like ultrasound assessment to evaluate effectiveness.

> *Exercise and physical activity build and maintain muscle strength and tone, they support joints, and it does decrease fatigue and increases mobility.*

◆

> *Skin rehabilitation is crucial for many for reasons: it prevents and reduces disability in the hands, it improves movement, it prevents and reduces disability in the face, and it improves self-executing.*

How to see the body through videocapillaroscopy?

Moderators: Michael Oeschger (SSc Patient, German Scleroderma Association, Germany), Maurizio Cutollo (Professor of Rheumatology, University of Genova, Italy)
Speakers: John Pauling (Consultant Rheumatologist at North Bristol NHS Trust, United Kingdom), Vanessa Smith (Associate Professor of Rheumatology at the Ghent University, Belgium), Maurizio Cutollo

The aim of the session was to present how videocapillaroscopy can be used to assess differences in the structure of finger capillaries between healthy participants and people with different levels of scleroderma. The method can detect a wide spectrum of abnormalities, including architectural issues with capillaries and enlarged capillary loops and connected areas.

John Pauling started the session with a lecture about the basics of how nailfold capillaroscopy works, describing it as a simple, safe and reliable tool that has an important role in the practical assessment of connective tissues diseases. Vanessa Smith and Maurizio Cutolo then proceeded with the practical part of the session. The first videocapillaroscopy was done on a healthy person, allowing the audience to understand what is being observed. The team then went onto the same presentations with several SSc patients experiencing differing levels of SSc and various involvement of hands in the disease progression. By the end of the session, the audience was able to correctly identify changes in capillary structure. The speakers also urged patients to regularly undergo videocapilarospopy as it is a very useful measurement of disease progression within the analysed area.

Life Hacks: Navigating Everyday Wins with Systemic Sclerosis

Speakers: Annelise Roennow (SSc Patient, FESCA Communications Manager, Denmark) and Monica Holmner (Vice-Chair of the Swedish Rheumatism Association for SSc and FESCA Board member, Sweden)

This practical session provided a comprehensive set of tips to improve daily life for individuals managing systemic sclerosis. Attendees also took part in the session to share personal useful tips and advice.

Some of the ideas shared will facilitate daily tasks, like using gloves when handling items in the fridge or freezer, employing tools to open jars easily, having a chair for resting while cooking or utilising a basket with wheels for easy movement while doing the laundry.

Speakers also shared some advice for travelling such as the importance of preparing adequately to ensure a smooth trip, to wear comfortable clothes and have a travel insurance to cover any unforeseen circumstances.

> *Look for further information not only for you, but for the people next to you and specially for caregivers.*
>
> ◆
>
> *Many easy tips can make patients’ lives easier.*

How should doctors tell their patients "You have Systemic Sclerosis"?

Moderators: Steffi Säurig (SSc Patient, Scleroderma Liga e.V., Germany), László Czirjak (Professor at the Department of Rheumatology and Immunology at the University of Pecs, Hungary)

Speakers: Kim Fligelstone (SSc Patient, FESCA Advisory Board member, United Kingdom), Masataka Kuwana (Professor and Director of Scleroderma/Myositis Centre of Excellence at Nippon Medical School Hospital in Tokyo, Japan), Michael Hughes (Consultant Rheumatologist at Salford Royal Hospital and Senior Clinical Lecturer at The University of Manchester, United Kingdom)

This session was an open discussion between patients and clinical experts on the importance of how to give a diagnosis.

Kim Fligelstone, a patient herself, discussed the emotional approach doctors should have when communicating with SSc patients. She emphasised the importance of empathy and clear communication and highlighted some examples of bad practices where doctors lack empathy and communicate in a cold, technical manner. She suggests that doctors should explain concepts like progressive disease, available treatments, and support resources to patients. The speakers further emphasised the need for simplifying medical language and addressing topics often omitted from consultations.

> *It is important to educate the family about the disease, not only the patient.*
>
> ◆
>
> *Some concepts can be really confusing for patients and doctors should try to simplify terms as much as possible.*

Breaking Ground: Exploring the Latest Frontiers in Systemic Sclerosis Research

Moderators: Sue Farrington (President of FESCA, Chief Executive of SRUK, United Kingdom)

Speakers: Christopher Denton (Professor of Experimental Rheumatology at University College London, United Kingtom), Marco Matucci Cerinic (Professor of Rheumatology at University Vita-Salute San Raffaele, President of the World Scleroderma Foundation, Italy) and Christina Bergmann (Physician and Rheumatologist at UniKlinikum Erlangen, Germany)

The final session of the conference provided a comprehensive overview of recent developments in systemic sclerosis research.

Professor Chris Denton delved into the progress made in pharmaceutical approaches to SSc treatment. He showcased recent trials and their significant impact on evolving treatment strategies, underscoring the substantial progress achieved in the field over the past couple of decades. Additionally, he highlighted the importance of employing clinical trial templates and patient-reported outcomes to standardise research methodologies.

Professor Marco Matucci focused on the evolution of systemic sclerosis diagnosis and the identification of early disease markers. He delved into the critical role played by antibodies and genetic predisposition in early disease detection, shedding light on ongoing research exploring microbiota and telomere length as potential biomarkers.

Christina Bergmann focused on CAR-T cell therapy, originally developed for tumour treatment, but now being explored for autoimmune diseases like lupus and systemic sclerosis. She provided an overview of the principle and procedure of CAR-T therapy. Initial findings in systemic sclerosis patients treated with CAR-T therapy revealed encouraging improvements in skin thickening and vascular phenotype.

Patient Congress Closing Session

Speakers: Ilaria Galetti (SSc Patient, Vice-President of FESCA, Italy), Michalea Linková (SSc Patient, Leader of Revma Liga, Czech Republic) and Maureen D. Mayes (Professor of Internal Medicine, University of Texas McGovern Medical School, Houston, USA)

The wrap up session reflected on the themes of interaction, sharing, and future directions. Speakers acknowledged the contributions of attendees, organisers, and supporters, expressing gratitude for their participation and dedication. Ilaria Galetti highlighted the importance of collaboration between clinicians, researchers, and patients, accentuating the evolution of medical discussions over the years into a more patient-focused approach.

Measures of success: Attendance

180 people registered to attend the Patient Congress. 141 participants attended exclusively the patient progress session, while many others that initially registered for the concurrent medical congress, also joined the patient program.

Attendees of the patient programme came from the following countries:

Country	Attendees
Andora	1
Belgium	4
China	2
Czech Republic	30
Denmark	1
Finland	5
France	1
Germany	10
Greece	1
Hungary	31

Country	Attendees
Ireland	1
Israel	1
Italy	3
Norway	1
Portugal	10
Spain	14
Sweden	5
Switzerland	2
The Netherlands	2
United Kingdom	6

Feedback from participants

After the congress had ended, all participants were offered the opportunity to share their feedback in an online form available in English, Spanish, Czech, Hungarian and German.

Below are some examples of how participants answered the question: “In your opinion, what was the best aspect of the Congress?”

“Meeting other patients and being able to discuss with professionals in SSC from across the world, in a setting intended for this purpose“

“Finally being together face to face again”

“Conviviality”

“Heartly welcome, appreciation, exchange”

“I was happy to be reunited with many people I hadn't seen for a long time, and I enjoyed sharing experiences with them”

“The human quality of the people who took part, both speakers and organisers”

“Meeting other people living with SSc after the pandemic”

“Patient leadership and engagement across all aspects”

“Networking and holding sessions together. Giving each other insights and sharing news”

“See and meet people with the same disease”

“Taking place at the same time of physician congress”

“Great chance to have famous speakers from the medical congress occurring at the same time”

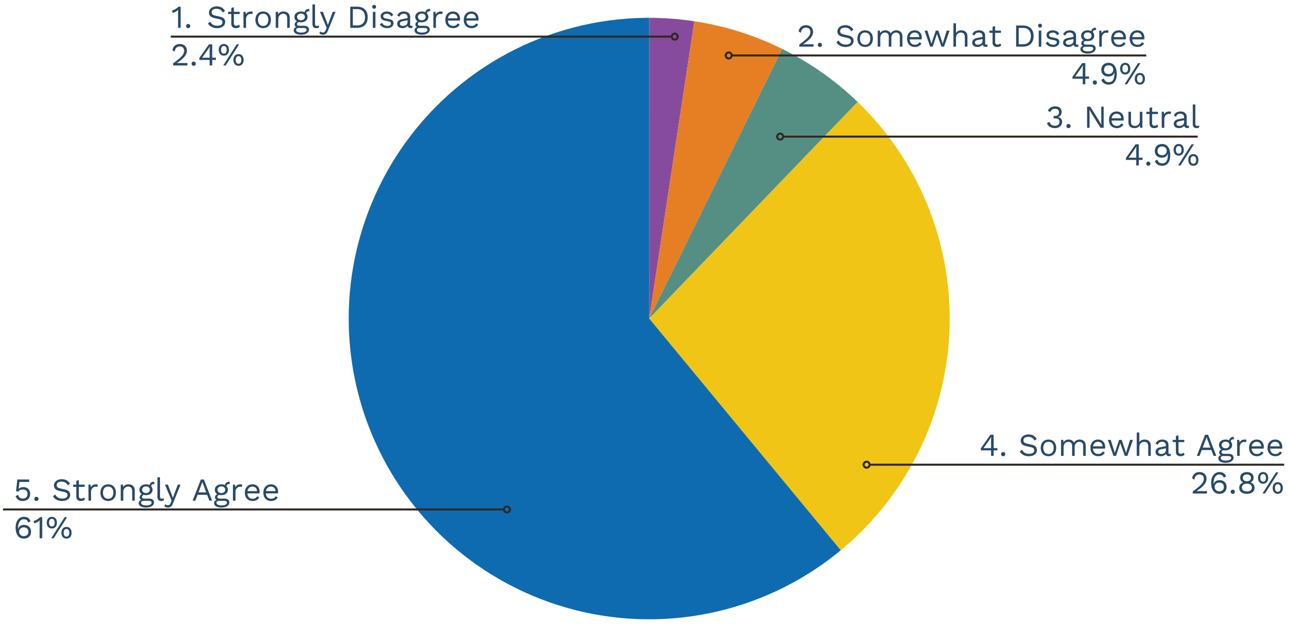
“Sharing experiences with other patients“

“Diversity of the sessions”

Below are some further statistics analysing the satisfaction of attendees based on the post-congress survey.

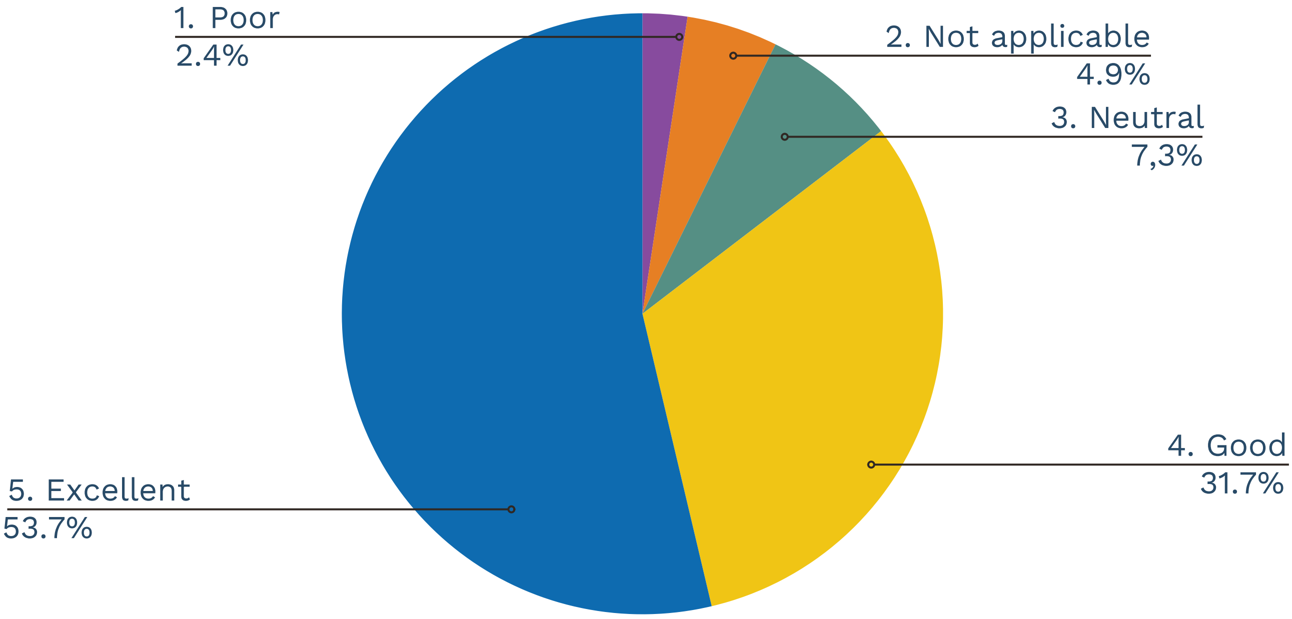
- 61% of attendees strongly agreed that the event met their expectations followed by 26.8% who somewhat agreed with the statement

Overall, the event met my expectations



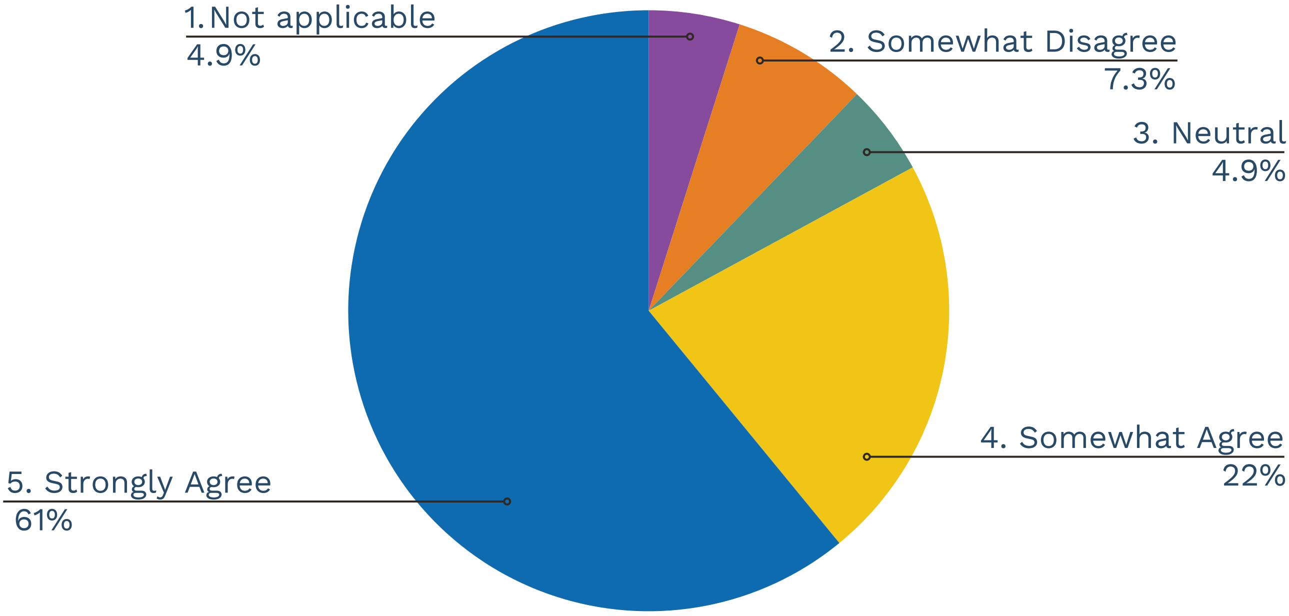
- The majority of respondents reported a positive perception of the program, with a significant proportion (85,4%) rating it as excellent or good

Satisfication with the overall programme



- 61% of the surveyed attendees strongly agreed that it was meaningful to hear and learn from the patients with another 22% agreeing with the statement.

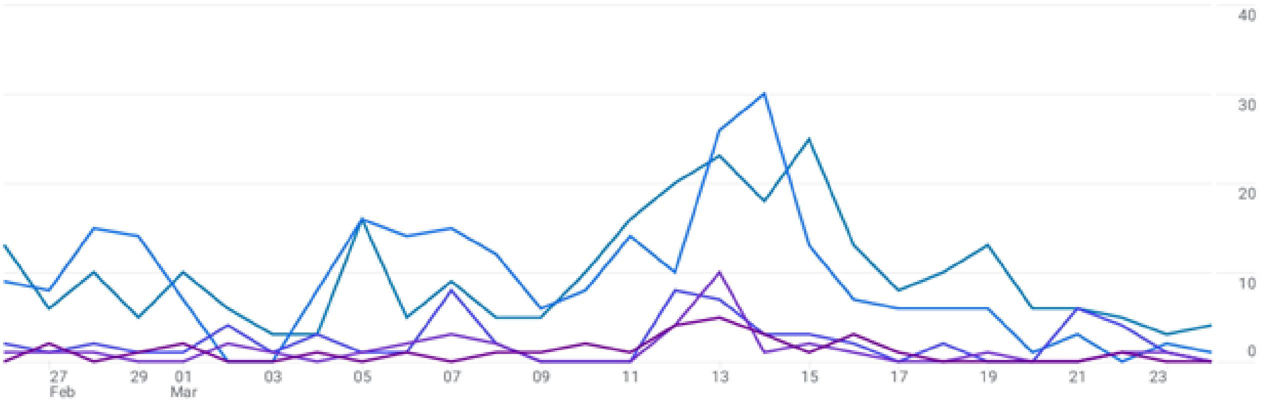
It was meaningful to hear and learn from patients



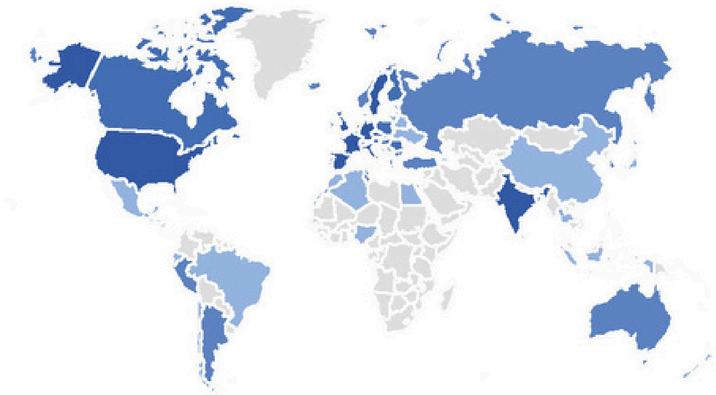
- Favourite sessions
  - The Gut Check: The Intestinal Tract and Microbiome in Systemic Sclerosis was the highest rated session of the Congress
  - From the breakout sessions, the highest rated one was Handy Solutions: Dealing with Hand Changes in SSc

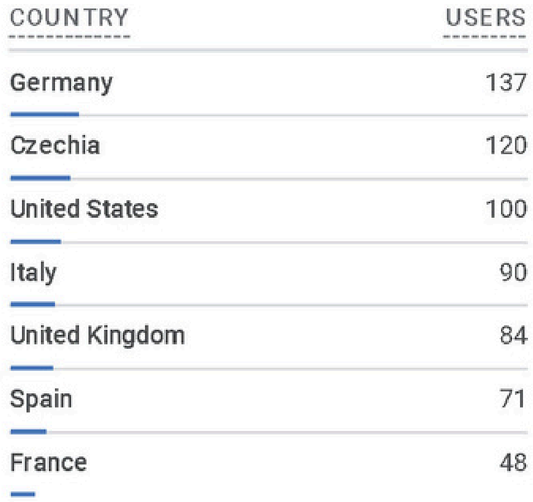
Online performance indicators

Daily FESCA Congress page visits in March (different lines reflect on different link sources):



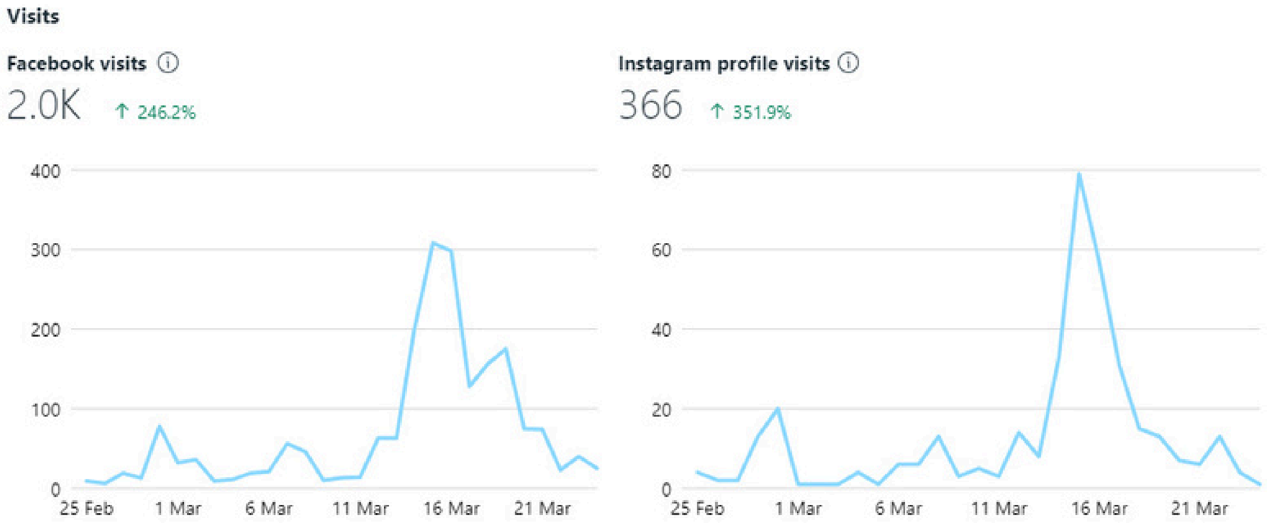
Which countries visited the FESCA Congress page in March?





COUNTRY	USERS
Germany	137
Czechia	120
United States	100
Italy	90
United Kingdom	84
Spain	71
France	48

How active were the FESCA social media channels?



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WE LOOK FORWARD TO SEEING YOU AT THE 9TH SYSTEMIC SCLEROSIS PATIENT WORLD CONGRESS IN ATHENS, GREECE IN 2026!