The Federation of European Scleroderma Associations

ANNUAL REPORT 2025

FESCA IVZW
Federation of European Scleroderma Associations

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Message from the President and Vice President

2025 has been a year of consolidation, visibility, and renewed ambition for the Federation of European Scleroderma Associations (FESCA). Across Europe, people living with scleroderma continue to face profound challenges — from delayed diagnosis and unequal access to specialist care, to the daily burden of invisible symptoms and isolation. In this context, FESCA's role as a united patient voice has never been more vital.

Guided by our strategic pillars of healthcare, awareness, education, and research, we have worked throughout the year to amplify patient perspectives, strengthen our network, and influence the systems that shape care and outcomes. Our "See the Unseen" World Scleroderma Day campaign brought invisible symptoms into sharper focus, reaching policymakers, healthcare professionals, and the wider public, while reinforcing the reality that scleroderma is a lifelong condition requiring sustained attention. The launch of our new website marked an important milestone in improving accessibility, connection, and information-sharing for our community.

Education remained central to our mission. From face-to-face patient advocate training in Milan to the patient-led planning of the 9th Systemic Sclerosis Patient World Congress, we continued to invest in empowerment, knowledge, and leadership across our member organisations. In parallel, our engagement in European policy, research collaborations, and partnerships with clinical and academic stakeholders ensured that the patient voice remained embedded in decision-making, innovation, and guideline development.

These achievements reflect the strength of our members, the dedication of our board and partners, and the resilience of the scleroderma community. As we look ahead, we remain firmly committed to equitable, timely, and high-quality care for all people living with scleroderma — wherever they live.

Sue Farrington PRESIDENT

Ilaria Galetti VICE-PRESIDENT

SFarrington

Ilaria Galetti

About FESCA

The Federation of European Scleroderma Associations (FESCA) is a pan-European umbrella organisation dedicated to advocate for Scleroderma patients.

Scleroderma is a rare and highly diverse disease encompassing various manifestations of connective tissue and vascular disorders. The disease presents significant challenges in treatment and care due to limited awareness, disparities in healthcare systems, insufficient social support, isolation from specialists, and gaps in medical knowledge about available therapies.
To drive meaningful change, it is essential to foster support, advocacy, and research by engaging a broad community of stakeholders.

- **Umbrella group of scleroderma patient organisations**
- **Amplifying the voice of scleroderma patients**
- **Empowering member organisations**
- **Sharing the best practice**

Our mission:

Our mission is to **raise awareness** of scleroderma and advocate for the highest **standards of treatment and care.**

We are dedicated to educating patients, clinicians, and the wider public, while representing national organisations at the European level to foster collaboration and promote equitable access to care.

Our efforts include active engagement with policymakers and the pharmaceutical industry, as well as supporting clinical, translational, and social research to improve outcomes for all those affected by scleroderma.

Our vision:

Our vision is a world where **everyone with scleroderma receives timely, effective, and equitable care** from fully informed healthcare professionals. We aim for greater awareness, reduced isolation for patients, consistent access to successful treatments across Europe and beyond, and ultimately a cure.

Looking ahead

FESCA is committed to making a tangible difference in the lives of people affected by scleroderma through advocacy, cooperation, and innovation. Our work is guided by a clear strategic vision focused on ensuring that **every person living with scleroderma has access to gold-standard therapy and care**, regardless of where they live.

This strategy is articulated around four core pillars, which shape our priorities and activities: healthcare, awareness, education and research.

We advocate for equal, timely, and sustainable access to the highest standards of treatment and care for all people living with scleroderma across Europe.

We work to increase awareness of scleroderma among key stakeholders, including policymakers, healthcare professionals, industry partners, and the wider public, to ensure the disease is better recognised and addressed.

We aim to improve knowledge and understanding of scleroderma among the community of patients, caregivers, and healthcare professionals.

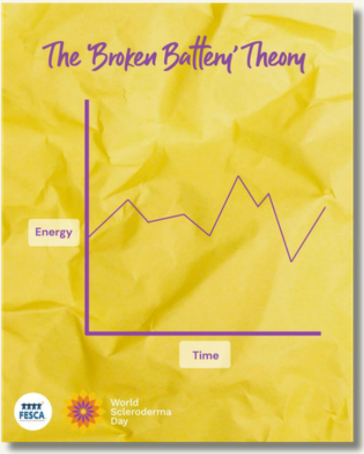
We promote the importance of pharmacological and non-pharmacological research, actively collaborating with industry and research partners to amplify the patient voice throughout the drug development and innovation processes.

What we did in 2025

Awareness

Social Media presence

FESCA continued to strengthen its social media presence by building on existing campaigns and diversifying content to increase engagement and awareness.



The Find the Light to Bloom campaign was extended through the strategic reuse of key assets, maximising its reach and long-term impact. At the same time, content formats were refreshed through the reimagined “Mythbusters” series, including “Did you know?” and “True or false?” posts, helping to share accessible and engaging information about scleroderma.

Patient empowerment remained central, with practical tips and advice informed by insights gathered from patient forums and online communities.

In parallel, FESCA expanded its content mix by introducing more educational and infographic-style posts, which contributed to higher engagement.

Outreach & Impact

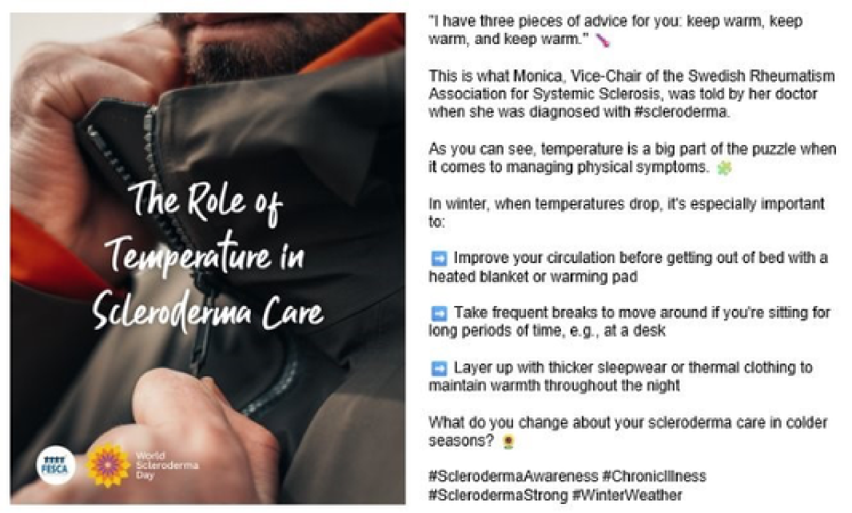
Over **700,000** views (600k,000 organic, 100,000 paid), **20,000** content interactions, and **1,000** new followers.

200,000 views, **13,000** interactions, and **720** new followers.

20,000 interactions and **720** new followers

Content hihglights

Best-performing posts featured strong visuals and accessible summaries of complex topics



"I have three pieces of advice for you: keep warm, keep warm, and keep warm." 🌡️

This is what Monica, Vice-Chair of the Swedish Rheumatism Association for Systemic Sclerosis, was told by her doctor when she was diagnosed with #scleroderma.

As you can see, temperature is a big part of the puzzle when it comes to managing physical symptoms. 🧩

In winter, when temperatures drop, it's especially important to:

➡️ Improve your circulation before getting out of bed with a heated blanket or warming pad

➡️ Take frequent breaks to move around if you're sitting for long periods of time, e.g., at a desk

➡️ Layer up with thicker sleepwear or thermal clothing to maintain warmth throughout the night

What do you change about your scleroderma care in colder seasons? 🌻

#SclerodermaAwareness #ChronicIllness #SclerodermaStrong #WinterWeather

World Scleroderma Day 2025 “See the Unseen”

Marking World Scleroderma Day (29th June), FESCA delivered the “See the Unseen” campaign, a one-month campaign across Instagram and Facebook (which was complemented by a paid campaign that took place in parallel on LinkedIn), to highlight the often invisible realities of living with scleroderma, including pain, fatigue, and limitations in daily life.

The campaign combined patient stories with educational content to strengthen understanding of the condition and reinforce the need for improved care and research. It also positioned FESCA as a leading voice within the rare disease community.

Objectives

- Make invisible symptoms visible, recognised, and impossible to ignore
- Increase awareness among key professional audiences and decision-makers
- Encourage earlier diagnosis and more comprehensive care
- Reinforce that scleroderma is a lifelong condition, extending beyond awareness moments

Awareness

Target Audience & Reach

The paid campaign on LinkedIn successfully reached key stakeholders, including Policy Officers, Board Members, and Advisors, with strong visibility across major EU institutions such as the European Commission and the European Parliament. The organic campaign on Facebook and Instagram targetted patients, caregivers and patient advocacy groups.

Performance & Results on LinkedIn

81,060 IMPRESSIONS

1.52% ENGAGEMENT RATE

1,229 ENGAGEMENTS

898 LINK* CLICKS

*Directing to FESCA Website

Awareness

The best-performing post, focused on the challenges of eating with scleroderma, generated 24,736 impressions, achieving the highest engagement and number of clicks.

Performance & Results on Facebook

176,638 IMPRESSIONS

5.08% ENGAGEMENT RATE

4,905 ENGAGEMENTS

96,538 REACH

Fesca - Federation of European Scleroderma Associations is with **Lenka Lalíková / Pho...**
Published by Sofie Rees · June 2, 2025

90% of people living with #scleroderma have never heard about the disease before starting to show symptoms.

Join us in changing that in the lead up to World Scleroderma Day on June 29th. 🌍

Every week in June, we're going to help you 'See the Unseen' about scleroderma by putting you in the shoes of someone living with the disease – shedding light on the invisible symptoms that shape their life.

Our mission is to show you what having a rare disease like scleroderma is really like, in hopes of improving education, research and care.

Follow FESCA to see the series unfold and share each post with your community to help us raise awareness! 🌻

#Scleroderma #WorldSclerodermaDay #WSD2025 #Awareness #RareDisease #ChronicIllness

fesca_scleroderma
29 June 2025

Liked by **mericiateles** and **others**

fesca_scleroderma Do you ever wonder how it would feel for your body to turn to stone?

People living with #scleroderma don't have to.

Performance & Results on Instagram

40,408 IMPRESSIONS

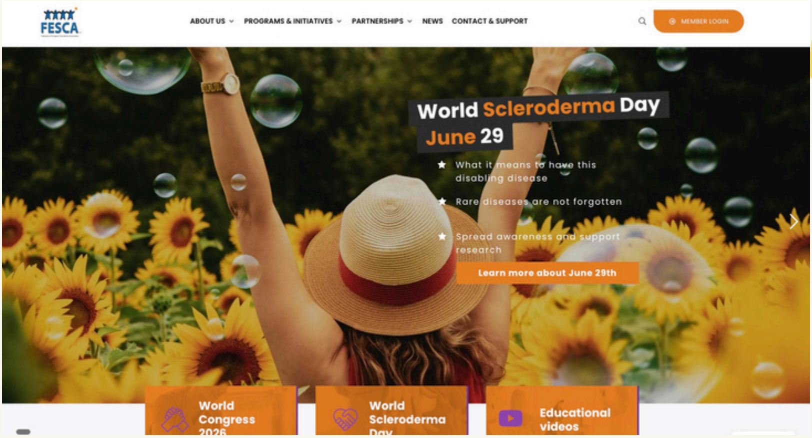
6.23% ENGAGEMENT RATE

1,478 ENGAGEMENTS

27,718 REACH

Awareness

Launch of the new FESCA website



World Scleroderma Day
June 29

- What it means to have this disabling disease
- Rare diseases are not forgotten
- Spread awareness and support research

In 2025, FESCA proudly launched its new website: https://fesca-scleroderma.eu. This initiative was driven by our commitment to increasing visibility for scleroderma and providing a modern, accessible platform for our community.

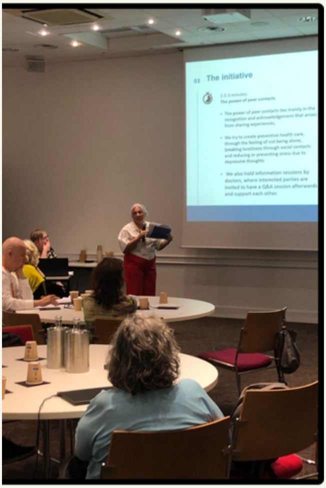
The new website offers a dedicated space for FESCA members, making it easier for organisations and individuals to connect, collaborate, and share important resources. Designed with user experience in mind, the site is easy to navigate and ensures that patients, caregivers, and professionals can quickly find the information they need.

Accessibility was a priority, with content tailored for patients and caregivers, including clear explanations, practical advice, and multilingual options. The website also serves as a hub for sharing valuable and trusted resources, supporting our mission to empower the scleroderma community with up-to-date knowledge and support.

With this new digital presence, FESCA strengthens its role as a leading voice in the rare disease community and continues to foster connection, education, and advocacy across Europe.

FESCA face-to-face training

FESCA organised a face-to-face patient advocate training in May in Milan, bringing together 24 patient advocates representing FESCA's national member organisations. The training served as both a capacity-building and networking opportunity, enabling participants to exchange best practices, strengthen their knowledge, and engage directly with leading experts.



The programme focused on the evolving role of patient advocates in healthcare systems, patient involvement in policy and decision-making, innovation in treatment and digital health, and emerging therapies in systemic sclerosis.

Through expert-led sessions and interactive discussions, participants gained practical insights to enhance their advocacy work at national and European levels.

Education

Training Highlights

Duties and Responsibilities of Patient Advocates - Isabella Brambilla
This session highlighted the role of patient advocates in addressing inequalities in access to care across Europe. Participants explored the shift from individual experience to collective representation and the importance of engaging effectively with healthcare systems, policymakers, researchers, and industry to ensure patient-centred decision-making.

New legislation: HTA and patient involvement – Salvatore Pirri
Participants were introduced to the basics of HTA and the new EU HTA Regulation. The session emphasised the importance of patient involvement in assessment processes and equipped advocates with key concepts to contribute meaningfully to discussions on access, reimbursement, and equity.

Exploring digital health & AI in healthcare - Eider Sánchez
This session provided an overview of digital health and AI in healthcare, highlighting their growing impact on clinical decision-making. It stressed the need for patient advocates to understand these rapidly evolving technologies to ensure innovation remains ethical, inclusive, and patient-focused.

Innovation therapies – CAR T and Stem Cell Transplants - Corrado Campochiaro
Participants gained insight into advanced therapies for systemic sclerosis, including stem cell transplantation and emerging CAR-T approaches. The session highlighted the potential benefits, limitations, and complexity of these treatments, as well as the importance of appropriate patient selection.

Education

Planning of the 9th Systemic Sclerosis Patient World Congress

In 2025, FESCA initiated the **planning of the 9th Systemic Sclerosis Patient World Congress**, taking place in **Athens, Greece, 6th-7th March 2026**, reaffirming our commitment to empowering patients and fostering global collaboration. A dedicated **Working Group** was established, comprising patients and patient advocates from across our network, ensuring that the congress is truly designed *for patients, by patients.*

The Working Group focused on **designing an agenda** that addresses the most pressing needs and interests of the systemic sclerosis community. The selection of speakers prioritized patient voices, alongside leading clinicians and researchers, to provide a balanced and comprehensive perspective.

The congress aims to strengthen the sense of community, promote knowledge exchange, and inspire advocacy at both national and international levels.

FESCA members played a central role in shaping the congress, from agenda design to speaker selection, demonstrating the power of patient-led initiatives in advancing care and support for those living with systemic sclerosis.

Healthcare

Policy Engagement 2025

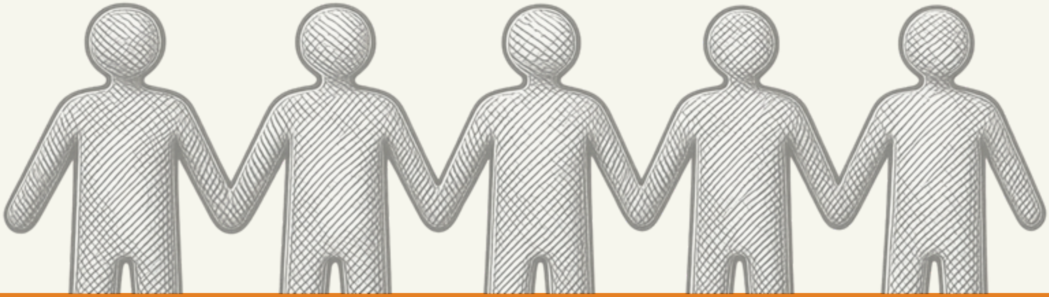
With key EU milestones approaching, including the Action Plan on Rare Diseases and the Strategy for the Rights of Persons with Disabilities, FESCA continued to strengthen its role in ensuring that the needs of people living with scleroderma are reflected in European policy and legislation.

Stakeholder engagement & visibility

FESCA maintained regular engagement with Members of the European Parliament (MEPs) and key stakeholders across relevant policy areas, including employment and social rights.

A key milestone was securing participation in the 2026 rare disease exhibition hosted by MEP András Kulja in Strasbourg.

Through visual storytelling, including photographs commissioned by the Czech Association, this initiative raised awareness of rare diseases and strengthened FESCA's visibility and positioning as a trusted EU policy partner.



Healthcare

Policy advocacy & contributions

Building on previous work, FESCA provided data, patient insights, and concrete recommendations to policymakers. This included:

- Contributing to the development of the EU Action Plan on Rare Diseases
- Engaging with experts and advisors involved in shaping European rare disease policy
- Monitoring and contributing to discussions on the EU Quality Jobs Roadmap and other relevant initiatives

Results

- Strengthened recognition of FESCA as a trusted partner and thought leader in rare disease policy
- Increased visibility of scleroderma among EU decision-makers
- Ensured alignment of systemic sclerosis priorities with the broader rare disease policy agenda

Research

FESCA plays an active role across the systemic sclerosis landscape, engaging with researchers, clinicians, and the pharmaceutical industry. Through collaborations with multiple industry partners, we contribute to projects and clinical trials while ensuring that the patient voice remains central. In every partnership, FESCA is committed to representing the lived experience of patients and advocating for the protection of their rights.

FESCA maintains a strong and ongoing collaboration with **EULAR** across various initiatives:

- Adherence Workingroup
- ERS-EULAR CTDs-ILD Guidelines
- EULAR study group on micro circulation
- EULAR update of SSc recommendations
- EULAR Education Workingroup
- EULAR PARE in Brussels
- EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis

FESCA is working closely with multiple partners on a number of joint initiatives:

- **ERN ReCONNET**
    - Working Group on the digital lesions project
    - Working Group on Research
- **EURORDIS**
    - Working Group on CPGs and patient pathways
    - DITA Task Force
- **ELF-EUPFF**
    - Working Group on Lung Fibrosis
    - Working Group on Transplant
- **Boehringer Ingelheim** Patient Engagement Panel
- Partners in many **EU projects**
- Co-authors in many **scientific publications**
- **Juvenile Scleroderma Symposium**

Research

- **Juvenile Scleroderma Research**

FESCA continues to support initiatives aimed at advancing research and knowledge in juvenile scleroderma, recognising the need for greater understanding and expertise in this area. To support this effort, Linda Schraven, FESCA Secretary, is part of the Juvenile Scleroderma Research Working Group and serves as a contact point for members interested in contributing to this work. We warmly encourage additional members to get involved, as increasing participation will be essential to building knowledge, sharing experience, and driving future research efforts.

Scientific Papers

- Guidance for stem cell therapy for juvenile systemic sclerosis patients. *Expert Review of Clinical Immunology*

Review

Guidance for stem cell therapy for juvenile systemic sclerosis patients

Ivan Foeldvari, Kathryn S. Torok, Juliana Silva, Christopher P. Denton, Jörg Henes, Paulina Horvei, Franziska Rosser, Catherine H. Orteu, Suzanne C. Li, Clare E. Pain, Tamás Constantin, Patricia Costa-Reis, Megan L. Curran, Maurizio Cutolo, Bernd Hinrichs, Kim Fligelstone, Susan Maillard, Pia Moinzadeh, Clarissa Pilkington, Linda Schraven & Vanessa Smith ...show less

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Cite this article https://doi.org/10.1080/1744666X.2025.2474216 Check for updates

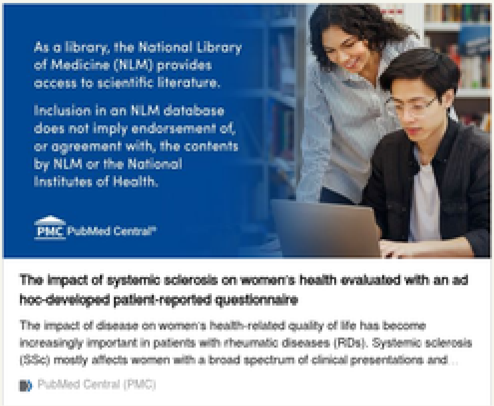
While most data on ASCT come from adult studies, the authors highlight the need to adapt adult criteria for pediatric patients, considering children's unique potential for recovery and tissue remodeling.

A multidisciplinary group of international scleroderma experts developed consensus guidance on when to consider ASCT and cellular therapies in jSSc. The resulting recommendations, largely adapted from adult data and informed by a survey of jSSc specialists, emphasise the importance of disease progression in selecting the right patients for these advanced therapies. The guidance aims to standardise inclusion and exclusion criteria and transplant protocols globally, enabling better comparison of outcomes across centers and ultimately improving care for children with jSSc.

Research

Other papers

- ERS/EULAR clinical practice guidelines for connective tissue disease
- A screening tool to detect interstitial lung disease in systemic sclerosis: the ILD-RISC score *Rheumatology*
- Clinicians' perspectives concerning treatment initiation and escalation strategies for digital ulcers in patients with systemic sclerosis *Journal of Scleroderma and Related Disorders*
- Physician–patient communication in the treatment of systemic sclerosis–associated interstitial lung disease: A narrative review and recommendations *Journal of Scleroderma and Related Disorders*
- *The impact of systemic sclerosis on women's health evaluated with an ad hoc-developed patient-reported questionnaire Journal of Scleroderma and Related Disorders*



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PMC PubMed Central®

The impact of systemic sclerosis on women's health evaluated with an ad hoc-developed patient-reported questionnaire

The impact of disease on women's health-related quality of life has become increasingly important in patients with rheumatic diseases (RDs). Systemic sclerosis (SSc) mostly affects women with a broad spectrum of clinical presentations and ...

PubMed Central (PMC)

Research

- Patients’ unmet needs and treatment preferences concerning digital ulcers in systemic sclerosis *Rheumatology*
- EULAR recommendations for the treatment of systemic sclerosis: 2023 update *Annals of the Rheumatic Diseases*
- Identification of red flags for IgG4-related disease: an international European Reference Network for Rare Connective Tissue Diseases framework *The Lancet Rheumatology*

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- Patient partnership model in rare and complex rheumatological conditions: research and beyond in European Reference Network ReCONNET. Lancet Rheumatol.
- "My world has shrunk": a mixed-methods exploration of the impact of systemic autoimmune rheumatic diseases on patients' lives. Rheumatol Int.
- The role of the patient in rheumatology. Nat Rev Rheumatol.
- How do doctors and patients communicate about the treatment of systemic sclerosis- associated interstitial lung disease? A plain language summary of publication. Ther Adv Respir Dis
- Comment on: The 2024 British Society for Rheumatology guideline for management of systemic sclerosis. Reply. Rheumatology (Oxford)

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- EULAR recommendations for the treatment of systemic sclerosis: 2023 update *Annals of the Rheumatic Diseases*
- Identification of red flags for IgG4-related disease: an international European Reference Network for Rare Connective Tissue Diseases framework *The Lancet Rheumatology*
- Patient partnership model in rare and complex rheumatological conditions: research and beyond in European Reference Network ReCONNET. *Lancet Rheumatol.*

Patient partnership model in rare and complex rheumatological conditions: research and beyond i...

In rare and complex connective tissue diseases, patient partnership is essential to address diagnostic delays,...

The Lancet Rheumatology

- "My world has shrunk": a mixed-methods exploration of the impact of systemic autoimmune rheumatic diseases on patients' lives. *Rheumatol Int.*
- The role of the patient in rheumatology. *Nat Rev Rheumatol.*
- How do doctors and patients communicate about the treatment of systemic sclerosis- associated interstitial lung disease? A plain language summary of publication. *Ther Adv Respir Dis*
- Comment on: The 2024 British Society for Rheumatology guideline for management of systemic sclerosis. *Reply. Rheumatology (Oxford)*

Directory of members

Currently, FESCA comprises 28 member organisations across 22 countries.

Country	Organisation	Country	Organisation
Austria	Sklerodermie Selbsthilfe e.V.	Israel	INBAR Association
Belgium	CIB-Liga vzw	Italy	AILS – Associazione Italiana Lotta alla Sclerodermia onlus
Belgium	APSB – Association des Patients Sclérodermiques de Belgique	Italy	ASSMAF – Associazione per lo studio della Sclerosi Sistemica e delle Malattie Fibrosanti
Bulgaria	Bulgarian Organization for Patients with Rheumatic Diseases- BOPRD	Italy	APMARR - Associazione Nazionale Persone con Malattie Reumatologiche e Rare
Croatia	HUOS – Hrvatska udruga oboljelih od sklerodermije	Italy	GILS – Gruppo Italiano per la Lotta alla Sclerodermia Padiglione Litta
Cyprus	Αντιρευματικός Σύνδεσμος Κύπρου (Cyprus Antirheumatic Association)	Netherlands	Nationale vereniging voor LUPUS, APS, Sclerodermie en MCTD
Czech Republic	Revma liga Revmatologický ústav	Norway	Norsk Revmatikerforbund
Denmark	Sklerodermiforeningen	Portugal	ADPE – Associação Portuguesa de Doentes com Esclerodermia
Finland	Suomen Sklerodermayhdistys Ry	Portugal	Liga Portuguesa contra as Doenças Reumáticas
France	Association des Sclérodermiques de France	Romania	Asociatia Pacientilor cu Sclerodermie din Romania
Germany	Sklerodermie Selbsthilfe e.V.	Spain	AEE – Asociación Española de Esclerodermia
Germany	Scleroderma Liga e.V.	Sweden	The Swedish Rheumatism Association Reumatikerförbundet
Greece	ELEANA-Hellenic League Against Rheumatism	Switzerland	Sclerodermie.ch
Hungary	Országos Scleroderma Közhasznú Egyesület	United Kingdom	Scleroderma and Raynaud's UK

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International Non-Profit Association
Registration No: FOJ 15454
Email: info@fesca-scleroderma.eu
Website: www.fesca-scleroderma.eu
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7500 Saint Maur BELGIUM

FESCA is member of:
EURORDIS
Rare Diseases Europe EPF
European Patients' Forum EULAR PARE

The Board
Sue Farrington- President
Ilaria Galetti-Vice-President
Linda Schraven - Secretary
Annelise Rønnow - Communications Manager
Monica Holmner - Board member

What is Scleroderma?

Systemic Sclerosis (SSc), also know as Scleroderma, is a rare, chronic and often progressive disease that affects the immune system, blood vessels, and connective tissue. Although it currently has no cure, it is neither contagious nor infectious, nor typically hereditary.

The exact cause of Scleroderma remains unknown. While it is not directly inherited, there may be a slight familial predisposition in those with a history of rheumatic conditions. The disease manifests in various ways, including the thickening and hardening of the skin and potential involvement of internal organs, excluding the brain. Diagnosing Scleroderma can be challenging because its symptoms differ widely among individuals and progress at varying rates.

Scleroderma can develop at any age, but it most commonly appears between the ages of 25 and 55 and Raynaud's phenomenon is often the first noticeable sign. Scleroderma is rare in children and affects women four times more often than men. The severity of the disease can range from mild to life-threatening.

While there is no cure, effective treatments are available to manage symptoms and improve quality of life. Organ-specific therapies can significantly help patients, though pulmonary arterial hypertension (PAH) remains a leading cause of mortality in severe cases.

How Many People Have SSc?

A disease is rare if affects fewer than 5 out of 10,000 people. However, the global epidemiology of SSc has not been thoroughly studied. Prevalence estimates vary by country, though it is generally believed that 10% of a population experiences Raynaud's phenomenon, with 2–7% of these cases progressing to Scleroderma.

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Appendix

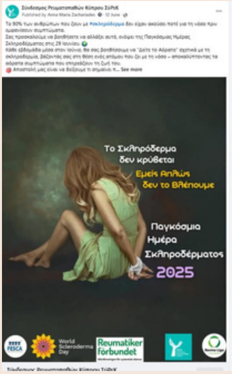
World Scleroderma Day – Initiatives from FESCA member organisations

Croatia - HUOS – Hrvatska udruga oboljelih od sklerodermije

For this year's World Scleroderma Day, the Croatian association created custom roll-up posters highlighting diagnoses and symptoms, utilizing the "See the Unseen" slogan. Members and volunteers gathered in Zagreb for a heartfelt awareness event, which drew coverage from several TV and radio stations. President Jadranka Brozd delivered an important statement, and members shared their personal experiences, stories that were also featured on social media.

Cyprus - The Cyprus League for People with Rheumatism

In Cyprus, World Scleroderma Day 2025 was marked by a dedicated social media campaign on Facebook, using FESCA-branded materials to raise public awareness, share patient stories, and promote WSD events and educational content. The Cyprus League of People with Rheumatism also organised a special tribute event, "A Life of Giving," on September 16, honoring the memory and legacy of Despo Charalambous, a founding member of FESCA. The event featured a lecture by Dr. Maria Heracleous on scleroderma's clinical presentation and modern management, and included a heartfelt recognition of Despo's family. Around 60 people attended, making it a meaningful occasion to celebrate Despo'scontributions and further educate the community about scleroderma.



Appendix

Czech Republic - Revma liga Revmatologický ústav

To celebrate World Scleroderma Day 2025, a Scleroderma Café gathering was held on June 28 in Prague. Twenty-five patients and their loved ones came together to enjoy coffee, tea, and refreshments in a warm, supportive environment.

The event offered attendees the chance to learn about the latest developments in scleroderma, explore treatment options, and discover available patient support. Participants could ask questions that often go unanswered in clinical settings and share their personal experiences openly with the invited experts, Assoc. Prof. MUDr. Martina Šterclová, Prof. MUDr. Michal Tomčík, Ph.D., and RNDr. MUDr. Mgr. Monika Slavíková Červinková, Ph.D. Their participation made the gathering both informative and uplifting for all involved.

Denmark - Sklerodermiforeningen

FESCA

Internationalt samarbejde

FESCA *increasing scleroderma awareness*

Federation of European Scleroderma Associations aisbl:
an umbrella group of scleroderma

On June 28, 2025, Denmark marked International Scleroderma Day with an event at Arena Randers, complemented by a month-long social media campaign on Facebook and Instagram. The day began with coffee and a discussion about the campaign images, followed by a presentation from Anne Braae Olesen of the Scleroderma Team, HUD, AUH.

Anne shared updates on CAR-T treatment research for scleroderma, interdisciplinary collaboration, and recent projects, including a study in Germany showing improvements for patients with diffuse cutaneous systemic sclerosis (dcSSc). Additionally, grant recipients Laura and Nanna presented their projects, Laura's on the structure of calcinosis and Nanna's on fecal transplantation (FMT) for chronic diarrhea in systemic scleroderma, with 13 out of 20 patients already participating. In total, 53 people attended in person, with 5 joining online, making it a valuable day for learning, sharing, and community building.

Appendix

France - Association des Sclérodermiques de France

In 2025, the French association organised 13 meetings across different cities to mark World Scleroderma Day. Each meeting focused on a variety of important topics, including updates on research, treatments, and clinical trials, as well as practical workshops on therapeutic education, managing digestive and pulmonary damage, and understanding the impact of scleroderma on different organs and aspects of daily life. Sessions also covered topics like fatigue, nutrition, sexuality, dermatology, and musculoskeletal issues, and included activities such as quizzes, art exhibitions, and music therapy. These gatherings provided valuable opportunities for patients and their families to learn, share experiences, and receive support in a welcoming environment.

Hungary - Országos Scleroderma Közhasznú Egyesület

The Hungarian Scleroderma Association celebrated World Scleroderma Day by launching the “See the Unseen” campaign alongside its 20th Jubilee National Conference in Pécs. The event featured presentations from leading experts and association leaders, covering the organisation’s history, mission, and the latest advances in scleroderma care. Highlights included talks on pregnancy and scleroderma, long-term disease management, new therapies, nutrition, lifestyle advice, and psychological support. The campaign was widely promoted on social media, increasing the association’s online following, and new creative materials were displayed in major rheumatology clinics and featured in the association’s newsletter.

Appendix

Italy – APMARR

In Italy, APMARR marked World Scleroderma Day 2025 by organising free screening days at hospitals and rheumatology clinics across the country. The initiative was supported by the creation and distribution of dedicated graphics and posters, which were also shared on social media and the organisation's website to maximize outreach and awareness. These efforts helped promote early detection, provided valuable information to the public, and reinforced APMARR's commitment to supporting people affected by scleroderma.

Portugal - The Associação Portuguesa de Doentes com Esclerodermia

The Associação Portuguesa de Doentes com Esclerodermia (APDE) planned a special event for patients, families, and healthcare professionals to mark World Scleroderma Day 2025. The program included health education sessions and interactive workshops, all designed to inform and support the scleroderma community.

Switzerland - Sclerodermie.ch

In Switzerland, sclerodermie.ch supported the World Scleroderma Day campaign by sharing translated materials and messages on social media, helping to raise awareness and engage their community throughout the country.

Appendix

Spain - Spanish Scleroderma Association

The Spanish Scleroderma Association (AEE) actively participated in FESCA's "See the Unseen" campaign for World Scleroderma Day 2025, using social media and symbolic photos to raise awareness about the often-invisible impact of scleroderma. Their efforts focused on educating the public, supporting patients and carers, and promoting early recognition of the disease, helping to make scleroderma more visible in society and healthcare.

The Spanish Scleroderma Association (AEE) actively participated in FESCA's "See the Unseen" campaign for World Scleroderma Day 2025, using social media and symbolic photos to raise awareness about the often-invisible impact of scleroderma. Their efforts focused on educating the public, supporting patients and carers, and promoting early recognition of the disease, helping to make scleroderma more visible in society and healthcare. The Spanish FESCA member also organised the Second National Congress of Scleroderma for patients, held in Santiago de Compostela. The event featured expert panels on disease management, pain, ulcers, calcinosis, lung involvement, CAR-T treatments, and healthy lifestyle habits, as well as a patient testimony. The congress was endorsed by leading Spanish medical societies and supported by several pharmaceutical companies, making it a key event for education and patient support.

Appendix

Belgium - CIB Liga and Sclerodermie.be

The Belgian organisations CIB Liga and Sclerodermie.be organised a symposium to highlight the often “invisible” impact of scleroderma, focusing on the emotional and social challenges patients face beyond physical symptoms. The initiative encouraged greater self-acceptance among patients and calls on healthcare professionals to see individuals as people, not just their disease.

SYMPOSIUM Relations, intimité et sclérose systémique
Relaties, intimiteit en systeemsclerose

samedi/zaterdag 28 mars/maart 2026 - 10h/u-17h/u - gratuit/gratis incl. lunch
Hôtel Pullman Bruxelles-Midi/Brussel-Zuid - Place Victor Horta Plein

"Langue différente, même maladie, même combat"

acceptations de soi
relations affectives
intimité et sexualité

"Andere taal, dezelfde ziekte, dezelfe strijd"

zelfaanvaarding
emotionele relaties
intimiteit en seksualiteit

INSCRIPTION OBLIGATOIRE
https://sclerodermie.be

INSCHRIJVING VERPLICHT
secretariaat@cibliga.be
scleroken@gmail.com

Greece - ELEANA-Hellenic League Against Rheumatism

The Greek organisation ELEANA-Hellenic League Against Rheumatism supported the “Hear the Unheard” campaign by translating the campaign materials into Greek to ensure accessibility for its members and wider community.

Παγκόσμια Ημέρα Σκληροδέρματος – 29 Ιουνίου 2025

Παγκόσμια Ημέρα Σκληροδέρματος

Είμαστε εδώ – μαζί, πιο δυνατοί από ποτέ

Τι σημαίνει «συνηγορία»

The organisation actively disseminated the campaign through its social media channels (Facebook, Instagram, and LinkedIn), as well as on its website. In addition, a press release was issued, resulting in 28 media clippings, significantly increasing the campaign’s visibility at national level.

FESCA

Federation of European Scleroderma Associations

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