9TH SYSTEMIC SCLEROSIS PATIENT WORLD CONGRESS

March 6-7, 2026 I Athens

EVENT REPORT

FESCA

Contents

Message from the President and Vice-President

We are delighted to present the official report of the 2026 World Scleroderma Patient Conference—a gathering that brought together patients, advocates, clinicians, researchers, policymakers, and industry partners from across Europe and beyond. This year's meeting in Athens reflected a shared conviction that lies at the heart of our work: **patients' needs, experiences, and voices must drive progress in systemic sclerosis.**

Over two days, participants engaged in discussions spanning early diagnosis, accelerating access to therapies, advances in emerging technologies, and the often hidden but deeply human aspects of living with this complex condition. The stories and perspectives shared were courageous, insightful, and profoundly moving. They reminded us once again that patient narratives are not anecdotes—they are essential data that guide better care, stronger policy, and more meaningful research.

We extend our deepest thanks to the speakers, volunteers, national associations, and the entire working group who shaped this outstanding programme. Your commitment ensures that our community remains informed, empowered, and united.

This conference exists because of—and for—every person living with scleroderma. As you read this report, we hope you feel the strength of our shared purpose and the momentum we continue to build together.

Thank you for being part of this journey.
President & Vice President
FESCA

Executive Summary

The **9th Systemic Sclerosis Patient World Congress**, organised biannually by FESCA (Federation of European Scleroderma Associations), is a leading international event dedicated to the scleroderma community. Since 2010, the Congress has become a vital platform for patient education, networking, and exchange of the latest research and lived experiences. Uniquely designed by patients, for patients, the Congress ensures that the voices and real-world insights of those affected by systemic sclerosis (also known as scleroderma) are at the heart of every session.

Bridging communities and advancing knowledge

The Congress is committed to bridging gaps between patients, clinicians, researchers, and industry partners. By fostering a collaborative and inclusive environment, it enables meaningful knowledge sharing and empowers all participants to contribute to the advancement of care and advocacy in systemic sclerosis (SSc).

Executive Summary

Patient expertise at the center

Sessions are tailored for a lay audience, ensuring accessibility and practical guidance to improve disease management and quality of life (QoL). Patient experts are embedded throughout the program, ensuring that patient perspectives are not only included but are central to the Congress. This approach bridges the gap between scientific advancement and lived experience, creating a synergy that encourages mutual understanding and the exploration of diverse viewpoints.

Fostering community and impact

Networking opportunities and collaborative sessions are designed to strengthen the patient community, promote knowledge sharing, and inspire collective action. The Congress underscores the importance of effective patient engagement and collaboration, emphasising that meaningful progress in SSc care can only be achieved together.

About the event

The 9th Systemic Sclerosis Patient World Congress took place in Athens, between 6-7th March 2026, as part of the broader Systemic Sclerosis World Congress. Hosted by FESCA, this unique event is specifically designed by patients, for patients, setting it apart from traditional medical congresses. The Congress brought together individuals living with SSc, their families, caregivers, patient advocates, clinicians, researchers, and industry representatives from across Europe and beyond.

The program featured an extensive and balanced agenda, including keynote presentations from leading experts, interactive sessions, and panel discussions. Sessions addressed a wide range of topics relevant to the SSc community, such as the latest advances in research and treatment, drug development, clinical practice, and the often-overlooked area of mental health and intimacy. Special emphasis was placed on practical guidance, lived experience, and patient empowerment.

A hallmark of the event was its interactive format, which encouraged open dialogue, networking, and the direct exchange of ideas and experiences.

Key achivements

2 days

> 180 attendees

24 countries

12 sessions

48 speakers

The congress was successfully held over two days, bringing together more than **180 participants** from **24 countries**, highlighting the strong global engagement of the SSc community.

The programme featured **12 sessions** delivered by **48 speakers**, offering a rich and diverse agenda that covered key topics across research, clinical care, patient experience, and advocacy.

A major strength of the congress was its diverse representation, with patients, caregivers, clinicians, researchers, and industry partners all contributing to the discussions. This multi-stakeholder approach fostered meaningful dialogue and a deeper understanding of the challenges and opportunities in SSc care.

Importantly, all sessions were designed and co-led by patient experts, ensuring that the programme remained grounded in real-life experiences and priorities of people living with the disease.

The congress also included practical and interactive sessions focusing on disease management, mental health, and patient advocacy, equipping participants with valuable knowledge, tools, and strategies to support both personal disease management and collective advocacy efforts.

ROUNDTABLE DISCUSSION: Accelerating Access: Breaking Barriers to Threapies

Moderator: Ilaria Galetti - *Patient Advocate* (IT) **Speakers:** Oliver Distler – *Healthcare Professional & Researcher* (CH) , Annie Gilbert - *Pharma Representative* (UK), Mary Wheatley - *Patient Advocate* (USA)

This first roundtable brought together representatives from key stakeholders (Clinicians, pharma representatives and patient advocates) to discuss how to accelerate access to medicines for SSc. The speakers emphasized the importance of **involving patients early in the design of clinical trials**, not only to ensure that studies address real patient needs, but also to improve recruitment, retention, and the overall success of trials. Annie Gilbert described how her team works closely with patients and site staff to design trials that are comfortable and accessible, highlighting the creation of long-term patient advisory boards and the use of "concierge services" (such as transport and accommodation support) to help patients from rural or underserved areas participate in studies. The discussion also covered the need for robust patient representation in trials, including caregivers and diverse populations, to ensure that results are meaningful and applicable to all who may benefit from new therapies.

Professor Oliver Distler explained that patient-centered trials are more likely to succeed, as patient input helps reduce barriers to participation and ensures that outcome measures reflect what truly matters to those living with the disease. The panel discussed the challenges of conducting trials in rare diseases, such as small patient populations and the need to balance robust data with inclusivity. They also addressed the importance of patient-reported outcomes (PROs) — both paper and electronic — and the value of decentralized or hybrid trial models, which can make participation easier and faster.

Mary Wheatley stressed that patient experience data is not just important, but essential: "Science can tell us whether a medication is effective and safe, but without people with lived experience, we don't know if it truly makes a meaningful difference. Capturing this experiential data can influence benefit-risk assessment, reimbursement decisions, and our understanding of what daily life is like with the disease. That context is critical, and the information that patients are able to share is truly vital."

The session concluded with a call for greater collaboration between pharmaceutical companies, patient organizations, and healthcare professionals to combat misinformation, improve trial awareness, and ensure that clinical research leads to real, meaningful improvements in patients' lives.

Outcomes and Programme Highlights

Keep on Moving: Prehab & Rehab

Moderator: Henrik Pettersson - *Healtcare professional* (SE) **Speakers:** Michael Oeschger - *Patient advocate* (DE), Maria Koulopoulou - *Healthcare professional & Researcher* (UK), Alain Lescoa - *Healthcare professional & Researcher* (FR), Kyriaki Keramiotou - *Healthcare Professional* (GR)

This session focused on the importance of physical activity, rehabilitation, and occupational therapy for people living with systemic sclerosis, especially when the disease affects the lungs. Speakers emphasized that SSc is a complex, multi-organ disease that requires a multidisciplinary approach and patient-centered care. The session highlighted that early and sustained rehabilitation, tailored to each patient's needs, can significantly improve mobility, hand function, and overall QoL. Consistency in exercise, even in small amounts, was shown to help maintain progress and prevent further loss of function, while stopping exercise leads to a rapid decline.

Maria Koulopoulou explained that rehabilitation pathways should be built on strong foundations and collaboration, with services tailored to patient needs and preferences. She encouraged patients to be active participants in designing their care and highlighted the importance of timely follow-up and multidisciplinary support.

Michael Oeschger shared his personal journey, describing how he went from severe disability to regaining independence through long-term physiotherapy and daily movement, and stressing that consistency is key and stopping exercise leads to rapid decline. He also described setbacks, the need to adapt intensity during flares or fatigue, and the value of combining exercise with medical supervision and regular monitoring.

Alain Lescoat highlighted that tailored, sustained exercise improves hand function and QoL, and that rehabilitation should be individualized and combined with medical treatment when needed. He presented evidence that the benefits of rehabilitation are lost if exercise is discontinued, and discussed new approaches like peer mentoring and digital tools to help patients stay motivated.

Kyriaki Keramiotou showed how occupational therapy helps protect hand function and independence, using practical strategies, assistive devices, and pacing, and emphasized that early and ongoing support makes daily life more manageable for patients.

Outcomes and Programme Highlights

VEDOSS: The Present and the Future of Early SSc Diagnosis

Moderator: Beata Garay - *Patient Advocate* (HU) **Speakers:** Marco Matucci - *Healthcare Professional & Researcher* (IT), Monica Holmner - *Patient Advocate* (SE)

This session focused on the importance and evolution of very early diagnosis in SSc. Professor Marco Matucci explained how the understanding of SSc has shifted over the past decades, from recognizing only advanced disease to now identifying and treating patients in the very earliest stages. He described the development of the VEDOSS project, which established criteria for recognizing SSc before significant organ damage occurs, using signs like Raynaud's phenomenon, puffy fingers, specific antibodies, and capillaroscopic changes.

The session also included a powerful patient perspective from Monica Holmner, who shared her personal journey of living for years with unexplained symptoms before receiving a diagnosis. She highlighted the emotional toll of uncertainty and the value of early information, not just for medical management, but for patient dignity, empowerment, and choice. The session concluded with a call for patient-centered approaches, clear communication, and ongoing research to further improve early detection and outcomes in SSc.

Taking Control: Self-Management of calcinosis and digital ulcers

Moderators: Luna Toppenberg - *Healthcare Professional & Researcher* (DK) **Speakers:** Tanaka Ngcozana - *Healthcare Professional & Researcher* (UK), Merce Piñero - *Patient Advocate* (SP), Michael Hughes - *Healthcare Professional & Researcher* (UK)

This session focused on self-management of calcinosis and digital ulcers in SSc, highlighting both the physical and emotional impact of these complications. Luna Toppenberg explained that calcinosis, painful calcium deposits in the skin, can cause chronic pain, infections, and loss of mobility, and that current treatments like sodium thiosulfate injections show promise for some patients but are not universally effective. She emphasized the need for more research.

Tanaka Ngcozana discussed the challenges of self-managing digital ulcers, noting the lack of specialist nurses and educational resources. She outlined practical steps for daily wound care, the importance of hygiene, and the need for patients to track their healing and recognize signs of infection.

Michael Hughes described the scientific background and management of digital ulcers and calcinosis, explaining that ulcers are often caused by poor blood flow and injury, and that both conditions can severely affect QoL. He highlighted the importance of early recognition, patient education, and a multidisciplinary approach, as well as the need for new local therapies and better drug options. Hughes also noted that surgery is sometimes necessary but not always effective, and that ongoing research is crucial.

Mercè Piñero shared her personal experience living with calcinosis and digital ulcers, describing the pain, daily challenges, and the trial-and-error process of finding effective treatments. She emphasized the value of patient education, peer support, and practical tools.

The panel discussion addressed pain management, the role of nutrition and supplements, and when to seek medical help. Speakers agreed that pain is often undertreated and that patients should advocate for stronger relief when needed.

Good nutrition, hydration, and hygiene are important for healing, and early intervention is key to preventing complications.

Breaking the silence: Intimacy living with SSc

Moderators: Linda Schraven - *Patient Advocate* (NL) **Speakers:** Cosimo Bruni - *Healthcare Professional & Researcher* (CH), Maria Grazia Lazzaroni - *Healthcare Professional & Researcher* (IT), Anne Schouffoer - *Healthcare Professional & Researcher* (NL), Kim Fligelstone - *Patient Advocate* (UK)

This session addressed the often-overlooked topic of intimacy and sexuality in people living with SSc. Anne Schouffoer opened by highlighting that symptoms like dryness, pain, fatigue, and changes in body image can have a major impact on relationships and self-esteem, yet these issues are rarely discussed with healthcare professionals. She emphasized the importance of open communication, practical strategies for managing dryness and discomfort, and the need for both patients and clinicians to break the silence around sexual health.

Maria Grazia Lazzaroni presented findings from a detailed questionnaire on women's health and sexual function in systemic sclerosis, revealing that about half of respondents reported a negative impact on their sex life, with vaginal dryness and other disease symptoms as key barriers. She noted that many women felt the topic was not relevant or were too embarrassed to discuss it, and stressed the importance of addressing contraception, pregnancy, and menopause openly with clinicians.

Cosimo Bruni focused on the male perspective, explaining that men with SSc may experience more severe disease and are also affected by sexual dysfunction, particularly erectile issues. He shared insights from focus groups, where men described how the disease affects their sense of masculinity, intimacy, and self-image.

Kim Fligelstone shared patient experiences, highlighting the wide range of physical and emotional challenges that affect intimacy, from pain and mobility issues to loss of libido and self-confidence. She reported that while some patients are able to talk to their partners about these issues, many feel their concerns are not resolved or are dismissed by doctors. Kim encouraged patients to seek referrals to specialists when needed and to try different approaches, emphasizing that sharing experiences and talking openly can help reduce stigma and improve QoL.

The session concluded with a discussion on the need for better education and support for both patients and healthcare professionals, the value of multidisciplinary care, and practical advice such as using lubricants, protecting sensitive areas, and not being afraid to ask for help. The speakers agreed that tackling intimacy in SSc requires breaking taboos, improving communication, and recognizing that sexual health is an important part of overall well-being.

Navigating GI complications: Funduplication, fecal incontinence and GERD

Moderators: Ilaria Galetti - *Patient Advocate* (IT) **Speakers:** Zsuzsanna McMahan - *Healthcare Professional & Researcher* (USA), Catarina Leite - *Patient Advocate* (PT), Yannick Allanore - *Healthcare Professional & Researcher* (FR)

This session focused on gastrointestinal (GI) involvement in SSc, a topic that remains under-researched despite its major impact on daily life.

Catarina Leite described how GI symptoms, such as difficulty swallowing, reflux, bloating, pain, and urgent need for the bathroom, are exhausting, often invisible, and can lead to social isolation and anxiety.

Professors Yannick Allanore and Zsuzsanna McMahan explained that GI complications are among the most disabling aspects of systemic sclerosis, affecting both limited and diffuse forms of the disease.

They discussed how the entire digestive tract can be involved. The speakers highlighted the need for multidisciplinary care, involving rheumatologists, gastroenterologists, and pulmonologists, especially when considering complex interventions like surgery.

The session covered practical strategies for managing symptoms, such as eating small, frequent meals, raising the head of the bed, staying upright after eating, and working with nutritionists.

For severe reflux or motility issues, combining acid blockers with promotility agents and considering newer medications may help. Pelvic floor physiotherapy and nerve stimulation were discussed as options for bowel control problems, and the importance of individualised dietary adjustments was stressed.

The panel also addressed the emotional burden of GI symptoms. They encouraged patients to ask for referrals to specialists and mental health support when needed.

Eat better, feel better: Understanding the role of diet in managing the disease

Moderators: Kristofer Andreasson - *Healthcare Professional & Researcher* (SE)
Speakers: Susanna Proudmann - *Healthcare Professional & Researcher* (AU), Elizabeth Volkmann - *Healthcare Professional & Researcher* (USA), Annelise Roennow - *Patient Advocate* (DK), Wendy Stevens - *Healthcare Professional & Researcher* (AU)

This session addressed the vital topic of nutrition and dietary management in SSc, bringing together international experts and patient advocates.

Susanna Proudmann's presentation, delivered by Wendy Stevens, highlighted that gastrointestinal symptoms are nearly universal in SSc and often lead to malnutrition, weight loss, and nutrient deficiencies. She emphasized that up to 30% of patients may experience malnutrition, which can worsen fatigue, infections, and wound healing. Proudmann recommended individualised dietary strategies, careful assessment by physicians and dieticians, and practical measures such as eating small, frequent meals, avoiding trigger foods, and considering supplements for common deficiencies like vitamins D, B12, and iron.

Kristofer Andreasson discussed how scientific research can inform practical dietary decisions, such as the benefits of lactose-free diets for those with intolerance, the impact of caffeine on Raynaud's phenomenon and reflux, and the importance of not overlooking other causes of gastrointestinal symptoms, such as cardiovascular disease or malignancy.

Elizabeth Volkmann focused on the gut microbiome, explaining how imbalances in gut bacteria (dysbiosis) can worsen inflammation, fibrosis, and GI symptoms. Volkmann encouraged patients to make gradual changes and to be kind to themselves when adapting their diets.

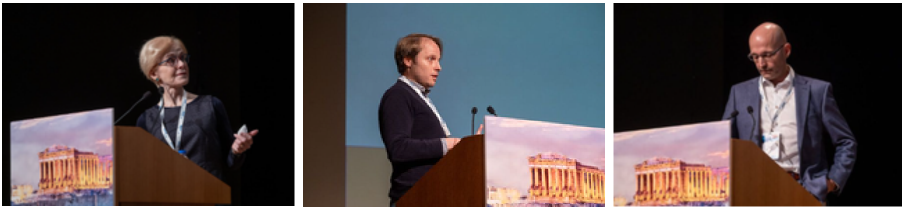
The session concluded that while there is no single "scleroderma diet," careful assessment, collaboration with healthcare professionals, and a willingness to experiment with dietary modifications can help patients manage symptoms, prevent malnutrition, and improve QoL.

Outcomes and Programme Highlights

Understanding CAR-T: Opportunities and challenges for Scleroderma Patients

Moderator: Maureen Mayes - *Healthcare Professional & Researcher* (USA) **Speakers:** Corrado Campochiaro - *Healthcare Professional & Researcher* (IT), Michael Oeschger - *Patient Advocate* (DE)

This session introduced the audience to the emerging field of cell-based therapies for systemic sclerosis, with a focus on CAR-T therapy. The session began with an overview of current immunosuppressive and cell-based treatments, explaining the difference between traditional therapies (like monoclonal antibodies) and newer approaches that use living cells to reset the immune system.



Corrado Campochiaro explained the principles of CAR-T therapy, where a patient's T cells are genetically modified to target and destroy harmful B cells. Campochiaro emphasized that CAR-T therapy is currently reserved for patients with severe, treatment-resistant disease and is only available in specialised centers. He discussed the challenges of selecting appropriate patients, managing risks, and the need for more research to understand long-term safety and efficacy.

Michael Oeschger highlighted that, despite advances in immunosuppressive therapies, many patients continue to face significant symptoms and unmet needs. Oeschger explained that CAR-T and other cell-based therapies represent a shift from chronic immunosuppression to the possibility of immune reconstitution, a potentially time-limited but high-risk intervention. He stressed the psychological impact of eligibility criteria, the emotional burden of being excluded from trials, and the importance of clear communication about risks, benefits, and realistic expectations. Oeschger also addressed the impact on caregivers, the high costs of treatment, and the need for equitable access if these therapies prove to be effective. He concluded by emphasizing that while CAR-T offers hope, it remains experimental and is only suitable for selected patients at this stage. Patient organizations play a key role in supporting individuals and translating complex scientific information into practical guidance.

The speakers highlighted the importance of ongoing clinical trials, careful patient selection, and collaboration between rheumatologists, immunologists, and specialized treatment centers to ensure safety and maximize benefits as these therapies evolve.

Artificial Intelligence in SSc: Empowering Patient Support

Moderator: Annelise Roennow - *Patient Advocate* (DK) **Speakers:** John Pauling - *Healthcare Professional & Researcher* (UK), Janet Pope - *Healthcare Professional & Researcher* (USA), Edith Brown - *Patient Advocate* (UK)

This session explored the rapidly evolving role of artificial intelligence (AI) in SSc, focusing on its potential to empower patients and support clinical care.

John Pauling discussed how AI can help reduce diagnostic delays by supporting patients in recognising symptoms and prompting earlier medical evaluation. He demonstrated how AI tools like ChatGPT can provide accurate information about Raynaud's phenomenon and systemic sclerosis, sometimes even outperforming primary care physicians in identifying red flags. Pauling also described how AI can help patients interpret complex medical letters, support clinicians in early diagnosis and prognosis, and assist with image analysis.

Janet Pope highlighted the everyday presence of AI in our lives, and showed how tools like ChatGPT can help patients, healthcare providers, and researchers access and interpret information. She emphasized the importance of not sharing personal data with AI tools and always consulting professionals for medical decisions.

Edith Brown highlighted how AI, particularly in the field of capillaroscopy, can improve diagnosis and monitoring, especially for patients in remote or underserved areas. She praised the collaborative efforts between clinicians, researchers, and patients in developing AI tools and stressed the importance of data protection and ensuring that AI solutions are inclusive and representative of diverse patient populations.

The session concluded that AI has significant potential to empower patients and clinicians, improve early diagnosis, and support personalized care in SSc. However, the speakers cautioned that users must remain critical, verify information with healthcare professionals, and be aware of the risks of misinformation and privacy concerns.

ROUNDTABLE DISCUSSION: What's new In SSc treatment

Moderator: Sue Farrington - *Patient Advocate* (UK) **Speakers:** Michael Oeschger - *Patient Advocate* (DE), Shervin Assasssi - *Healthcare Professional & Researcher* (USA), Brian Lee – *Pharma representative* (USA)

This roundtable brought together diverse perspectives to discuss the latest advances and ongoing challenges in SSc treatment.

Michael Oeschger noted that while treatment options have improved, most therapies still focus on managing symptoms rather than altering the disease course. He emphasized the need for innovations that prevent irreversible organ damage and called for therapies that can truly modify the long-term outlook for patients.

Brian Lee described the pharmaceutical industry’s efforts to develop new therapies, including cell-based treatments like CAR-T that aims to reset the immune system. He acknowledged the challenges of safety, access, and costs, noting that these therapies are complex, require specialized centers, and involve significant logistical and financial barriers. Lee stressed the importance of industry collaboration with patients, caregivers, payers, and policymakers to ensure that new treatments are accessible.

Dr. Shervin Assassi emphasized the need for personalized medicine, molecular profiling, and smarter treatment strategies. He advocated for moving away from a one-size-fits-all approach and using biomarkers, autoantibodies, and clinical subtypes to tailor therapies to individual patients.

The session concluded that while new therapies offer hope for transforming SSc care, significant challenges remain in terms of access, personalisation, and long-term safety.

Feel better to live better

Moderator: Catarina Leite - *Patient Advocate* (PT) **Speakers:** Rita Shrimer - *Healthcare Professional & Researcher* (NL), Janet Poole - *Healthcare Professional & Researcher* (USA)

This session focused on the broader concept of well-being, emphasizing that living better means more than just controlling symptoms.

Rita Shriemer gave a presentation on identity, explaining how living with SSc can disrupt both personal and social identity. She encouraged participants to reflect on their evolving identities, embrace new roles, and prioritise what matters most to them. She also discussed the opportunities for growth and advocacy that can arise from living with a chronic disease. Janet Poole then provided practical tips for managing stress and anxiety, highlighting the importance of self-management, goal setting, and seeking professional support when needed. She explained the difference between stress and anxiety, described how they can impact pain, fatigue, and daily activities.

The session concluded that living better means embracing emotional well-being, autonomy, and hope, and finding meaning and participation in life despite the disease.

Feedback Summary

4.42/5 Satisfaction with the Congress Programme

4.30/5 Satisfaction with the Congress Organization

4.05/5 Satisfaction with the networking opportunities during the Congress

The overall satisfaction with the Congress was very high across all evaluated dimensions. The programme and content received an average score of 4.42 out of 5, reflecting strong appreciation for the scientific and educational value of the sessions.

Event organisation and the congress venue both scored 4.30 out of 5, indicating a consistently positive experience in terms of logistics and setting.

Attendance levels were notably high, demonstrating strong engagement from participants. **90.4% attended all or most sessions**, with more than half (55.8%) attending all sessions. This reflects a high level of interest and commitment throughout the Congress.

90.4% attended all or most sessions
80.8% reported gaining new knowledge or insights
92% are very likely to recommend the Congress to other patients

Feedback Summary

All Congress sesssions scored over 4.0/5

Eat better, feel better: Understanding the role of diet in managing the disease **4,64**

Navigating GI complications: Fundoplication, fecal incontinence and GERD **4,63**

Breaking the silence: Intimacy living with SSc **4,50**

The Congress also had a strong educational impact. A total of 42 out of 52 respondents (80.8%) reported that they gained new knowledge or insights.

In addition, 46 out of 50 respondents (92%) indicated that they would be very likely to recommend the Congress to other scleroderma patient advocates, demonstrating a high level of overall satisfaction and endorsement.

The qualitative feedback highlights recurring themes for improvement. One of the key themes is the perceived separation between patients and healthcare professionals, with repeated calls for more integrated formats, including shared sessions, access to poster areas, and opportunities for direct interaction.

Regarding additional topics for future editions, participants most frequently mentioned mental health, patient empowerment, and further information on treatments and disease management. There was also interest in expanding coverage of specific clinical aspects, as well as complementary approaches to living with the disease.

Testimonials and Feedback

Being newly diagnosed, this was a first time for me to attend the SSc Patient World Congress. Coming from the US, it was a great experience meeting and having great conversations with people from western and Eastern European countries. Listening to the panelists that are actively engaged with new research gave me encouragement that researchers/physicians and pharmaceutical companies are working together with patients to help subside or stop further damage.

It was an eye opener experience, I gained not only knowledge but hope as well. It was so much more than I had hoped for

Keep on moving. Hope must always remain

Even after over 30 years of living with SSc I can still learn something useful to help me navigate this debilitating disease/condition and hopefully improve my QOL

Inspiring

Gold medaille worth

As a clinician and researcher one of the most important aspects of participating in the congress is the shared patient experiences. It brings further insights, confirming knowledge and deepens my resolve in the importance of patient participation in research

Global collaboration is essential in rare diseases. When patients, clinical, and organizations share knowledge and experiences, we create stronger pathways for awareness, research and better care for the systemic sclerosis community.

Educational

Thank You

The success of the **9th Systemic Sclerosis Patient World Congress** was only possible thanks to the commitment of the organisers, the dedication of the Working Group members, and the generous support of sponsors.

Through our collective efforts, we successfully delivered another annual patient conference, aimed at sharing key up-to-date information, raising awareness, and continuing to educate the patient community in Europe.

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