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## World Scleroderma Foundation and European Scleroderma Trials and Research Group Jubilee

The celebrations of the tenth anniversary of the World Scleroderma Foundation (WSF) and the twentieth anniversary of the European Scleroderma Trials and Research group (EUSTAR) were held on 30 May 2023 in the halls of the Leonardo da Vinci National Museum of Science and Technology (Museo Nazionale della Scienza e della Tecnologia Leonardo da Vinci) in Milan. The WSF is a non-governmental, non-profit foundation established in Switzerland with the aim of initiating, developing and supporting research into systemic scleroderma and supporting patients with the disease. The WSF is committed to improving the quality of life of patients and conducting research, as well as cooperating with other organisations and associations to achieve these goals while remaining independent of regional authorities, political organisations and industry. Among its objectives, the WSF pursues its goals by organising world congresses on systemic scleroderma, supporting research projects, providing research grants, setting up expert teams and supporting education on systemic scleroderma. The *Journal of Scleroderma and Related Disorders* is the official organ of the WSF.

The idea of multicentre collaboration in systemic scleroderma research originated at the end of the 20<sup>th</sup> century. In 2002, the EUSTAR group was established with Marco Matucci Cerinic from Florence as one of its main initiators. Florence was also the venue for the group's working meetings and the first Systemic Sclerosis World Congress. In 2004, EUSTAR was awarded the status of an EULAR-supported group and the name of the group was the acronym for EULAR Scleroderma Trials and Research. According to the EULAR statutes, the research group should

have become independent after ten years, which posed a problem for the EUSTAR group because the pharmaceutical industry was less interested in systemic scleroderma than in other diseases. After the establishment of the WSF, the group became part of the WSF and changed its name to European Scleroderma Trials and Research while retaining the same acronym. Today, EUSTAR brings together more than 200 clinical and research centres working on the disease and holds an immense database, which has been instrumental in publishing more than 50 valuable scientific papers that significantly advance various aspects of systemic scleroderma. EUSTAR also organises training courses and activates young researchers.



Figure 1. Milan, 30 May 2023. Dame Carol Black accompanied by Przemysław Kotyla and Eugeniusz J. Kucharz

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**Figure 2.** Milan, 30 May 2023. From right: Przemysław Kotyla, Maurizio Cutolo, Eugeniusz J. Kucharz, Daniel Furst, Anna Kotulska-Kucharz

The anniversary celebrations began with a short film, after which the audience was welcomed by Marco Matucci Cerinic, for many years the tireless *spiritus movens* of the worldwide movement for research on systemic scleroderma. This was followed by a presentation by Thomas Krieg on the WSF research grant system, and then he and Ulrich Schanbacher introduced this year's scientific award winners. This year, additional special research grants were awarded to young scientists from Ukraine, enabling three of them to carry out work in Italy and one in France.

The next item on the agenda was a session led by Piet van Riel and Sue Farrington presenting the history, achievements and plans of WSF and EUSTAR. The opening lecture was delivered by Dame Carol Black. It was entitled: "The Pillars of Scleroderma" and spoke about the pioneers of research on systemic scleroderma, including Stefania Jabłońska. The background of the founding of EUSTAR and WSF was interestingly presented by Allan Tyndall, and the history of EUSTAR courses was discussed by László Cziráj. It was nice to hear him speak warmly about the course held with the support of the Polish Society of Rheumatology in Katowice in 2015, as well as about the participation of Poles (lecturers and trainees) in training during the courses. Yannick Allanore told the story of cooperation between EULAR and EUSTAR. Daniel Furst presented the history of the development of classification criteria for systemic scleroderma, Ulf Müller-Ladner spoke about the DeSS-cipher study aimed at optimising therapeutic strategies, and the participation of a group of young researchers in the work of EUSTAR was presented by Corrado Campochiaro,

Michael Hughes, Maria Grazia Lazzaroni and Tania Santiago.

The current EUSTAR leaders (Francesco Del Galdo, Marie Elise Truchetet, Madelon Vonk) presented the current activities and future plans of the group.

Masataka Kuwana (one of the two editors-in-chief) discussed the development of the "Journal of Scleroderma and Related Disorders", and Maurizio Cutolo presented a brief outline of the history of capillaroscopy and its application in the diagnosis of systemic scleroderma. The sessions were concluded by Marco Matucci Cerinic, recalling, among other things, the links with the family of Paul Klee (1879–1940), a painter who suffered from systemic scleroderma. His grandson, Alexander Klee, supported the establishment of the WSF and also gave permission to use the star motif from two of Paul Klee's paintings in the emblems of EUSTAR and the WSF. The ongoing interaction of the WSF and EUSTAR with the patient associations affiliated with the Federation of European Scleroderma Associations (FESCA) was also mentioned.

The last element of the conference component of the jubilee were speeches discussing the philological aspects of the term TEAM (Gianluca Giadima di Maulo Errico) and orchestra as an example of teamwork (Irina Khodosevitch). It should be mentioned that the motto of the meeting, and in a sense of all activities of the WSF and EUSTAR, are the words once uttered by Frank Wollheim: "United we win".

After a coffee break in the museum's columned hall, the participants listened to a piano concert and then attended a gala dinner held in the museum's gallery, in a former monastery building.



**Figure 3.** EUSTAR emblem featuring a star motif from a painting by Paul Klee

There was no shortage of Polish highlights at the ceremony. Since the first years of EUSTAR's establishment, Polish physicians and Polish rheumatology centres have participated in its work. The most significant contribution to the international movement for the research of systemic scleroderma has been made by Otylia Kowal-Bielecka, who was unable to come to Milan. She is the coordinator of the successively updated therapeutic recommendations and has also participated in many of EUSTAR's research and organizational projects. During the presentation of past and present activities of the WSF and EUSTAR, the successful organisation of the 2015 scleroderma course in Katowice was mentioned, and in the historical part, the contributions of Stefania Jabłońska to the understanding of systemic scleroderma as well as the International Conference on Scleroderma and Scleroderma-Like Diseases held on 24–28 June 1991 organized by Stanisław Sierakowski and Krystyna Bernacka and colleagues in Świeradów-Zdrój were mentioned. In backstage



**Figure 4.** WSF emblem also featuring a star motif from a painting by Paul Klee

conversations, scientific visits to Poland were warmly recalled by Dame Carol Black, Maurizio Cutolo, Daniel Furst and László Czirják, among others. Poles have taken an active part in all previous Systemic Sclerosis World Congresses. The jubilee meeting in Milan was attended by invited Polish rheumatologists Przemysław Kotyla, Anna Kotulska-Kucharz and Eugeniusz J. Kucharz.

Systemic scleroderma is a disease that persistently hides its secrets. Recent years have shown that despite many difficulties and gaps in the understanding of its pathomechanism, we can increasingly treat and diagnose the disease earlier and help our patients in a variety of ways.

## **ARTICLE INFORMATIONS AND DECLARATIONS**

### **ACKNOWLEDGMENTS**

None.

### **CONFLICT OF INTEREST**

None.