



BUILDING A NEW INTERNATIONAL CONGRESS AND BOOSTING THE FIGHT AGAINST A RARE DISEASE

A new Impact Story from AIM Group International

Milan, 8th May 2018 – AIM Group International, a leading company in the organisation of congresses, meetings and events, presents a new **Impact Story** about the **World Scleroderma Congress**, the first international congress exclusively dedicated to this rare disease, built from scratch with the World Scleroderma Foundation several years ago. It ended up with a won challenge: five editions have been organised, the last one recently in Bordeaux, with great results.

*“The Congress contributed significantly to the fortune of the World Scleroderma Foundation (WSF) at different levels (image, awareness, organisation, fund raising, etc.). The Congress and its positive outcome are the result of a **shared effort** by the scientific world and the PCO”* says **prof. Marco Matucci Cerinic**, World Scleroderma Foundation and Congress’s Chairman.

Scleroderma is a rare and serious disease and for a long time has only been on the agenda of Rheumatology Congresses. In 2010, a small group of specialised professors decided to **dedicate a congress** exclusively to this complex disease and to the improvement of the life of those affected. The main goals, in particular, were to **give visibility to the illness, raise funds, develop research**, find new medical treatments and support scleroderma sufferers.

It has been a challenge because **rare diseases attract less attention and funds**, and it meant **building the entire project from scratch** as there is not any other similar conference dedicated to Scleroderma worldwide.

AIM Group took the challenge and, thanks to its active relationships with the **rheumatology community and the pharmaceutical sector**, put its experience, network and knowledge towards making a successful event.

“Designing and realising an educational congress for a rare disease needs a different approach in terms of commitment and teamwork,” explains Francesca Manzani, Head of AIM Group Florence Office. *“The **dialogue between all the different stakeholders** -the committee, researchers, patient communities and sponsors – is even more important in this case and **all the AIM Group team was completely engaged** in finding effective initiatives to **provide a solid future for this event**”.*

One of the main features of the 3-days congress is that it gathers **not only physicians, health professionals and researchers but also patients** affected by this impactful disease. *“The connection between physicians and patients makes this congress really original, with a **patient-oriented point of view**. Also, the patients’ involvement means a different organisational approach: it means that **two parallel congresses** have to be realised, with a particular attention to **ethics standards** and a strict compliance”* outlines Manzani.

The first world congress was held in 2010 in Florence and then every two years, Madrid in 2012, Rome in 2014, Lisbon in 2016, and **Bordeaux** in 2018, with **1.250 attendees from 61 countries**.

The main initial goal has been achieved: a new world congress has become a **consolidated reality**, a biennial reference appointment for the community, rotating throughout the Europe. The results have always been extremely satisfying. These congresses have contributed to increasing knowledge of scleroderma throughout the world. The **number of countries** represented has grown by 10% as well as the number of **abstracts** received (450). Furthermore, new educational formats have been introduced through the years, making the knowledge sharing more effective. Also, the last edition was supported by **numerous new sponsors** and a **new fundraising activity** was promoted, with the goal of **leaving a legacy** to the World Scleroderma Foundation.

*“This **complex project** demonstrates that even in case of a rare disease it is possible to overcome difficulties and achieve significant results thanks to a strategic vision, a **strong commitment and active collaboration** among all stakeholders”* outlines Patrizia Semprebene Buongiorno, vice president AIM Group International.





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