

SKIN DEEP

All the scans confirmed a serious but little-known disease. Treatment would need to be bold and unique. Nothing short of... the birth of a congress. Words by **Rob Spalding**

Medical professors are not known for their frivolity. So when, in 2010, a small group of them decided that scleroderma should be elevated from an agenda item at rheumatology congresses to a major annual gathering of its own, it was no joke.

That was how the biennial World Scleroderma Congress was founded, together with the support of leading rheumatology organisations throughout Europe.

AIM Group International, the Milan-based association management and congress organiser, was appointed to oversee the first ever world congress in Florence in 2010. Since then, Francesca Manzani, Head of the AIM Group's office in Florence, took over: in Madrid in 2012, Rome 2014, Lisbon 2016 and in February this year, Bordeaux. Prague awaits in 2020.

Prof Marco Matucci Cerinic, chairman of the World Scleroderma Foundation and Congress, is based in Florence at its medical centre of excellence specialising in rheumatology and sclerosis. He was in no doubt about the efficacy of

the Bordeaux meeting. "It reinforced and demonstrated the high scientific quality of our event. Also, the fundraising activity organised with the support and initiative of our local host colleagues generated a funding which will be the background for a call for grants at international level."

Back in 2010 there was no precedent, so the event had to be built from scratch. However, the AIM Group enjoys close relationships with the rheumatology community and the pharmaceutical department of the company used its experience and contacts to create a successful first congress. Eight years later

Bordeaux attracted 1,250 attendees from 61 countries.

The congress meant a lot to the destination. "This major international congress was very important for us," attested Johan Defranoux, sales manager at the Bordeaux Congress Centre (BCC). "First, the congress was resolutely international. Secondly all areas of the BCC were equipped to accommodate this big event, which required important

logistics and management of conferences and workshops spaces because of an exceptionally busy programme. Finally, the congress was a success. Participants and organisers were satisfied as much by the quality of the organisation as by the choice of the destination."

The size of Bordeaux was something organisers had to bear in mind. "In a medium-sized city like Bordeaux the advantages are the walking distances between the main points, less traffic and a quiet environment," recalled Manzani. "But of course, since the providers are less used to managing major international events, it was necessary to fine-tune the solutions and share them in advance with the local providers. It was worthy work which ensured the smooth realisation of the event."

There was something special about the Bordeaux congress and its financial outcome. "The WSF will be able to continue its research thanks to such results," declared chairman Cerinic. "And our hope is that our studies and researches will lead to a cure for

Scleroderma (skleer-oh-DUR-muh)

A group of rare diseases that involves the hardening and tightening of the skin and connective tissues – the fibres that provide the framework and support for the body.



Delegates in session (top) and in plenary (below)

World Scleroderma Foundation supporters:

European League Against Rheumatism EULAR

European Rheumatology Association

European research centre EUSTAR

Federation of European Scleroderma patients associations FESCA



Top: registration at the BCC; below: delegates absorb posters; right: knowledge at their fingertips



scleroderma. Finding the treatment – at this stage – will be an enormous result, as much as finding the causes of the illness."

Adopting the concept of inclusiveness, the organisers set about creating not one but two congresses which, over three days, brought together physicians, health professionals, researchers and – crucially – patients affected by this much-misunderstood disease. "Regarding content, the connection between physicians and patients makes this congress really original and particularly rich in human empathy," explained Manzani. "The presence of patients over the years has contributed to maintaining a greater attention to their needs and helps in making improvements to their daily lives. It is embracing a patient-oriented point of view. It means that two parallel congresses had to be realised, as physicians and patients celebrate their own plenary sessions and seminars, but also need some shared moments."

Accordingly, several medical offices were set up and equipped to receive patients and make diagnoses, with other rooms arranged differently for the hands-on workshops. A social dinner was hosted at the Chateau Giscours and the fundraising dinner, organised by the local host committee, at the beautiful 18th-century Bordeaux City Hall, thanks to the City Council.

"I AM GLAD WE CAN SHOW THIS CASE HISTORY IN AMI MAGAZINE. RARE DISEASES HAVE SO LITTLE ATTENTION FROM THE PUBLIC AND THE INDUSTRY AND THIS SHOWS HOW MUCH CONVENTIONS AND DEBATES CAN HELP THE COMMUNITY TO APPROACH AND DISCUSS HOT ISSUES"

Patrizia Semprebene Buongiorno
Vice president of the AIM Group

This year the plenary session's welcome speech by the Foundation's president was followed by a video message from Alexander Klee of the Klee family, patron of the WSF, a particularly moving moment since the famous painter, Paul Klee, is believed to have suffered from a systemic sclerosis disease.

In Bordeaux there was much talk of legacy, largely due to the promotion of a new fundraising activity aimed at leaving an endowment to the World Scleroderma Foundation, which is not only initiating and supporting research into the disease but is also committed to improving the quality of life for scleroderma sufferers and their families. ■