

PATIENT PROGRAMME

SECOND WORLD SCLERODERMA CONGRESS

Madrid, 2-4 February, 2012

Duration of Congress: 2 days of sessions, 3 & 4 Feb, preceded by optional opening ceremonies on 2 Feb

Opening of SSc Congress on Thursday, February 2, 2012

13.00 **Opening speeches**

13.30 **Opening lectures**

- What has happened since WSCI in Florence? - Professor Dame Carol Black
- Two years in review: Novel Developments in Translational SSc Science: Dr. Sergio Jimenez, Dr. Oliver Distler, Prof. Chris Denton

14.30-16.00 **Roundtable Networking Meeting for Leaders of Patient Groups**

- CEOs, Presidents, V-Ps, Board Members and all other association leaders are welcome to this networking session, which will be conducted as an informal discussion.
- 5-min presentations are accepted for this networking session in advance. Please contact anntkennedy@gmail.com

18.00 **Opening Ceremony of the Congress & Cocktail Reception**

- This may be held in a different venue in old Madrid (not the congress hall), and we do not know how warm it will be. Patients will be greeted at the venue by a welcome team, who will inform patients as to the temperature. Dress warmly!

The Medical Programme of lectures continues separately from the Patient Programme for 2 more days. Patients may attend these lectures if they wish, in addition to, or instead of, their own lectures. The Patient Programme will be translated simultaneously into two languages, Spanish and French.

Patient Programme, Friday February 3, 2012

9.00 - 9.05 **FESCA Welcome/Introduction** Ann Kennedy

9.05 - 9.20 **What is Scleroderma, and Why Me?** Dr. Oliver Distler

9.20 - 9.30 Describing & Measuring SSc for the WHO Dr. Leslie Ann Saketkoo

9.30 - 10.40 **The Gastrointestinal Tract**

Chair: Dr. Nemanja Damjanov; FESCA Co-Chair: Catherine Van den Bosch

9.30-9.50 GI involvement: Dr. Dinesh Khanna

9.50-10.10 Nutrition therapy in SSc: Dr. Gabriela Riemekasten

10.10-10.40 Questions to the Panel

10.40-11.00 **How to Use Survey Results** Maureen Sauvé, Scleroderma Society of Canada
Including questions

11.00 -11.30 *Coffee Break*

11.30-13.00 **Vascular Problems**

Chair: Dr. Dan Furst; FESCA Co-Chair: Annelise Roennow

11.30-11.50 Secondary Raynaud's: Prof. Ulf Mueller-Ladner

11.50-12.10 Digital Ulcers: Prof. Marco Matucci-Cerinic

12.10-12.30 Wound Care: Barbara Gemmell, SSc nurse

12.30-13.00 Practical Hands-On session: Francesca Braschi, SSc nurse

13.00-14.00 *Lunch*

14.00-15.15 **Cardiopulmonary Issues**

Chair: Dr. Rick Silver; FESCA Co-Chair Gabriella Verzi

14.00-14.25 Issues with the Lungs: Prof. Loïc Guillevin

14.25- 14.50 Problems in the Heart: Dr. Gerry Coghlan

14.50 -15.15 Questions to the Panel

15.15-16.30 **Living With Scleroderma**

Chair: Ann Kennedy, FESCA; Co-Chair: Dr. Alan Tyndall

15.15-15.45 Tips on Self-Management: Kim Fligelstone

15.45-16.00 Going Back to Work: Despo Charalambous-Demetriou

16.00-16.15 Coming to Terms with My Life with SSc: Annelise Roennow

16.15-16.30 Interactive session/Open discussion

Saturday, February 4, 2012

9.00-9.45 **The Importance of Clinical Trials**

Chair: Ann Kennedy; Co-Chair: Dr. Dominique Farge

9.00-9.25 Stem Cell Therapy: Dr. Alan Tyndall

9.25-9.40 The Patient Perspective on Stem Cell Transplant: Gabriella Verzi

9.40-9.45 Questions to the Panel

9.45-11.00 **Sexuality and Pregnancy**

Chair: Prof. Ulf Mueller-Ladner; FESCA Co-Chair: Grazia Tassini

9.45-10.15 Sexuality in SSc for Men & Women: Dr. Ulrich Walker

10.15-10.35 Pregnancy: Dr. Antonio Brucato

10.35-10.45 The Patient Perspective: Johanna Berglind de Backer

10.45-11.00 Questions to the Panel

11.00-11.30 *Coffee Break*

11.30-12.00 **Juvenile Scleroderma** Dr. Ivan Foeldvari
Including questions

12.00-13.00 **Musculo-Skeletal Issues**

Chair: Prof. Laszlo Czirjak; FESCA Co-Chair: Manuela Perez Perez

12.00-12.30 Doc Spot: Professor Chris Denton

12.30-13.00 Questions to the Panel

13.00-14.00 *Lunch*

14.00- 15.30 **Coping with Chronic Disease**

Co-Chairs: Ann Kennedy and Kim Fligelstone

14.00-14.20 How to Deal with Psychological Issues: Dr. Linda Kwakkenbos

14.20-14.30 Achieving Self-Esteem: Catarina Leite

14.30-14.40 Remaining Cheerful: Nadine Paciotti

14.40-14.50 Going Out Socially Once Again: Elaine Furst

14.50-15.00 Choosing to Do What I Can: Catherine van den Bosch

15.00-15.30 Interactive Panel on self-esteem/quality of life

15.30-16.30 **Physiotherapy and Exercise**

15.30-15.50 Physiotherapist Will Gregory

15.50-16.10 Occupational Therapist Janet Poole

16.10- 16.30 Physiotherapist and FESCA member Jadranka Brozd, who will lead relaxation exercises

18.15-18.30 **Closure Speeches of Medical and Patient Congresses**

Optional

20.00 **Medical & Patient Congress Gala Banquet**

Tickets may be purchased at Registration