

## PATIENT PROGRAMME

3rd WORLD SYSTEMIC SCLEROSIS CONGRESS, 6-8 FEB, 2014

### Opening of Patient and Medical Congresses on Thursday, February 6

- 17.00-18.30 Round-table Networking Meeting for Leaders of Patient Groups in Room Tarragona**  
All patient association leaders and/or representatives are welcome to this informal discussion to exchange ideas. No powerpoint presentations. Pre-registration by email preferred. English is the language of the meeting; no translation will be provided this day.
- [13.30-15.30 Hands-on training workshops for doctors, with patient volunteers as subjects: Nailbed Capillaroscopy and Skin-Scoring. Rooms on level-1.]**
- 18.45-20.30 Opening Ceremony of both Medical and Patient congresses, with lectures on “Basic and Translational Progress” and “The Patient Perspective”**
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*The Medical Programme is conducted separately from the Patient Programme. The Patient Programme in Keynote Room Orange will be translated simultaneously into Italian, French, and Spanish, and consist of presentations and discussions. Unless otherwise noted, sessions are in Room Orange.*

### Patient Programme, Friday February 7

- 9.00-9.10** FESCA aisbl. Welcome –Ann Kennedy
- 9.10 - 9.30** Why did I get scleroderma and will I be cured? – Jaap van Laar
- 9.30 - 10.30 Breathing**  
Chairs: Beata Garay-Toth and Ulf Mueller-Ladner
- 9.30-9.50 Why is breathing so difficult? Oliver Distler
- 9.50-10.05 The patient perspective on lung problems: Kim Fligelstone
- 10.05-10.30 Questions--Interactive session
- 10.30 -11.00 Coffee Break*
- 11.00-11.45 Nutrition and the Gut**  
Chairs: Nadine Paciotti and Dinesh Khanna
- 11.00-11.20 What can I do to help digestion processes? Janet Pope
- 11.20-11.35 Tips for people with GI problems: Susie Hoare
- 11.35-11.45 Questions
- 11.45-12.30 Sexuality and Pregnancy**  
Chairs: Despo Charalambous-Demetriou and Gabi Riemenkasten
- 11.45-12.05 Sexuality and Pregnancy in SSc: Angela Tincani
- 12.05-12.25 How I had a baby: Johanna Berglind and Jessica Thonen-Velthuisen
- 12.25-12.30 Questions--Interactive session
- 11.45-12.30 Concurrent session in Room Alcantara: Juvenile Scleroderma**  
Chair: Kim Fligelstone  
Panel: Ivan Foeldvari and Clare Pain and Linda Schraven  
*This is an interactive session for parents and young people with scleroderma to ask questions. In English. No translation will be provided.*
- 11.45-12.30 Concurrent session in Room Treviri: For Men Only**

Chair: Kent Krarup

Panel: Richard Silver, Richard Dodds and Joep Welling

*This is an interactive session for men with scleroderma to ask questions of the panel. No women. In English. No translation will be provided.*

12.30-14.00 Lunch

#### **14.00-15.00 Systemic Treatments**

Chairs: Ann Kennedy and Jaap van Laar

14.00-14.20 Transplants of different kinds—are they for me? Alan Tyndall

14.20-14.30 A patient perspective on transplants: Gabrielle Verzi

14.30-14.40 My story, my transplant: Jessica Thonen-Velthuisen

14.40 -15.00 Questions--Interactive session with the panel

#### **14.00-15.00 Concurrent session in Room Spalato: Breathing Exercises**

Physiotherapist Jadranka Brozd gives an interactive workshop on how to improve breathing

#### **15.00-16.00 Exercise and Therapies**

Chairs: Alexandra Portales and Tony Redmond

15.00-15.15 Hand and face exercises: Will Gregory

15.15-15.30 Dentistry in SSc: Roberto Rozza

15.30-16.00 Useful equipment and tips: Annelise Roennow, followed by questions to panel

20.00 Patient Dinner (*Pre-registration required. Some tickets may also be available at registration desk*)

### **Patient Programme, Saturday, February 8**

**9.00-9.15 New EULAR-ACR classification of SSc** Frank van den Hoogen

#### **9.15-10.00 Concurrent Sessions New Treatments in Scleroderma:**

In English, in **Room Orange**: Chris Denton

In French, in **Room Alcantara**: Yannick Allanore (In French; no powerpoints)

In Spanish, in **Room Spalato**: Patricia Carreira (In Spanish; no powerpoints)

In Italian, in **Room Merida**: Marco Matucci (In Italian; no powerpoints)

#### **10.00-10.45 Ulcers and the Hands**

Chairs: Grazia Tassini and László Czirájék

10.00-10.20 What can be done for my digital ulcers? Marco Matucci-Cerinic

10.20-10.35 Taking care of your ulcers: Barbara Gemmell

10.35-10.45 Questions to the Panel

#### **10.00-10.45 Concurrent Session in Room Spalato: Workshop in methods of facial camouflage**

10.00-10.20 Lasers & corrective make-up for telangiectasia & more: Dr Antoine Fauconneau

10.20-10.45 Questions and Answers: Dr Antoine Fauconneau and Pr Marie-Sylvie Doutre

10.45-12.00 Small Group Workshops continue in this room until 12.00

10.45-11.15 Coffee Break

#### **11.15-12.00 What are your Concerns? Ask the Professor**

Chairs: Ann Kennedy and Joep Welling

Panel: Chris Denton and Janet Pope

Interactive session. Written questions in advance would be appreciated.

### **12.00-13.30 Coping with Scleroderma**

Chairs: Annelise Roennow and Els van den Ende

12.00-12.10	Carers and Family members—Robyn Simms
12.10-12.25	Coping with the emotional aspects of SSc—Brett Thombs
12.25-12.45	Fatigue and how to deal with it— Janet Poole
12.45-13.30	Questions for the panel on coping with SSc

### **13.30 Closure of Medical and Patient Congresses**

**14.00 FESCA aisbl AGM for official representative of each member organisation, in Room Treviri . FESCA AGM continues on Sunday morning.**

#### **Ongoing Activities**

Patient Poster session

#### **Tables/desks set up in Room Pola**

- Table for Professor Falconneau, giving advice in camouflage makeup
- Table for EUSHNet health professionals, giving advice
- Table for SPIN project, to describe tools
- Table for DeSScipher materials and banner
- Table for Scleroderma Framed
- Table for FESCA administration, selling dinner tickets, etc.
- Display stands of leaflets etc.

#### **Locations**

- *All the patient congress sessions are at Level minus-1 of the hotel. Make sure that you take the correct elevator, at the back wall of the hotel, or use the stairs. Other elevators only go up to the rooms.*
- *The plenary room we will use for the patient congress will be **Orange**, at level minus-1 with elevator service. The room can seat a total of 400 people.*
- *In front of this plenary room are smaller rooms: 2 of 40 seats (**Treviri; Alcantara**) and 2 of 80 seats (**Spalato; Pola**). Another 2 rooms, one of 40 and one of 60 seats (**Efeso; Merida**) are in the same area but a little further away. These will be used for workshops on Feb 6, and for patient sessions on Feb 7 & 8 (with no AV facilities). Room Treviri will also be used for our AGM on Saturday afternoon and Sunday morning.*
- *Coffee breaks for patients are in the same area*
- *Lunch on Friday for patients is in the restaurant of the hotel, next to the hall on the ground floor. Congress delegates are not provided lunch on Saturday.*