

## PATIENT PROGRAM

4<sup>th</sup> WORLD SYSTEMIC SCLEROSIS CONGRESS, 18-20 FEB, 2016, Lisbon

### Opening of Patient and Medical Congresses, Thursday 18 Feb

15.00-17.00 Round-table Networking Meeting for Leaders of Patient Associations

Theme: "Patient Participation"

18.00-22.00 Opening Lectures and Welcome Reception for clinicians and patients

### Patient Programme, Friday 19 Feb

9.00-9.10 FESCA welcome: *A. Kennedy (Ireland)*

9.10 - 9.30 What Do we Know about Scleroderma Now? *Prof. C. Denton (UK)*

9.30 - 10.30 What will Help my Digestive Problems?

- Understanding the GI tract *Prof. J. Clarke (USA)*
- Nutrition in SSc *A. Cardoso (Portugal)*
- Learning to Cope with Gut Problems *A. Vegh (Hungary)*
- My Journey *I. Galetti (Italy)*

Chairs: *A. Kennedy (IE), C. Denton (UK)*

### **9.30 - 10.00, Parallel Session Room 3B:**

**New SSc Classification and Management Recommendations** *Prof. F. Van den Hoogen (NL)*

Chair: *J. Welling (NL)*

### **10.00 -10.30, Parallel Session Room 3B: Scleroid – a New Patient-Reported Outcome Measure**

*Dr. R. Dobrota (CH), Dr. M Becker (D)*

Chair: *K. Fligelstone (UK)*

10.30 -11.00 *Coffee Break*

11.00-12.00 What will Help me Breathe Easily? Is my Heart Involved?

- Understanding lung problems *Prof. O. Distler (CH)*
- PAH and the Heart *Dr. A. Cordeiro (Portugal), Dr. M.J. Loureiro (Portugal)*
- Struggles with Breathing *A. Roennow (Denmark)*

Chairs: *A. Portales (SP), Dr. A. Herrick (UK)*

### **11.00-12.00, Parallel Session Room 3B: EU projects with FESCA as partner**

- DeSScipher *Prof. U. Mueller-Ladner (D)*
- The Value of Patient Participation *Prof. Y. Allanore (FR)*

Chair: *B. Garay-Toth (Hungary)*

12.00-13.00 Can I improve my sexual relations, or get pregnant safely?

- Improving Sexuality *Prof. A. Tincani (IT)*
- Is it Safe to get Pregnant? *Prof. V. Steen (USA)*
- My New Baby *C. Leite (Portugal)*
- Developing Sexual Confidence *G. Verzi (IT)*
- Enjoying your Relationship *R. Kanters (NL)*

Chairs: *A. Kennedy (IE), T Ngcozana (UK)*

**12.00-13.00, Parallel Session Room 3B: For Men with SSc and Husbands of those with SSc**

- What will Help Men cope with SSc? *Prof. S. Santos (Portugal), J. Welling (NL)*

Panel Discussion in English and Portuguese, Chair: J. Welling (NL)

13.00-14.00 Lunch

**14.00-14.40 What will Cure the Pain of Digital Ulcers & Calcinosis?**

- Our Recommendations for Treatment of Ulcers *Prof. M. Matucci-Cerinic (I)*
- How we Care for Ulcers in a Portuguese Clinic *Prof. J. Delgado Alves (Portugal)*
- Pain: The Greatest Struggle for Many Patients *Y. Courcoux (F)*

Chairs: D. Charalambous (Cy), E. Mateus (Portugal)

**14.40-15.15 How do I Cope with my Facial Changes?**

- Changing Faces and Self-Esteem *Prof. A. Tyndall (CH)*
- Readjusting my Life *M. Sauv  (CAN)*
- My Story *S. Sandulescu (Romania)*

Chairs: B. Garay-Toth (Hungary), Prof. P. Carreira (SP)

**14.00-15.00, Parallel Session Room 3B: Juvenile Scleroderma**

- Moving On from SSc *Dr. I. Foeldvari (D), G. Verzi (I), A. Alferes Pereira (P)*

Panel Discussion, Chair: K. Fligelstone (UK)

**15.15-16.30 How Can I Manage SSc Myself?**

- Coping with the Everyday Challenges of Scleroderma *Dr. L. Kwakkenbos (NL)*
- Do Support Groups Help? *V. Delisle (CAN)*
- Painful Symptoms that Cannot be Measured *Dr. Jason Lee (CAN)*
- Mind & Body Strength *Dr. L.A. Saketkoo (USA)*

Chairs: N. Paciotti (CH), Dr. M J Salvador (P)

**15.00-15.30, Parallel Session Room 3B**

- Caring for your Teeth in SSc *Dr. A. Pequeno* (in Portuguese)

Chair: H. Gaspar (Portugal), A. Portales (SP)

**15.30-16.30, Parallel Session Room 3B**

- Scleroquizz Game (in English and French) *Nurse A. Noullez (F), Nurse G. Wojtasik (F)*

**9.00-15.00, Parallel Session Room 3A: Interactive Workshops -- Exercises to Improve Breathing and Facial Flexibility**

*Therapists: J. Brozd PT (Croatia), Viktorija Mišura PT (Croatia) and S. Roskar (Croatia)*

**9.30-10.10** Breathing Exercises; **10.15-10.45** Face Exercises; **11.00-11.45** Face Exercises; **12.00-13.00** Breathing Exercises;

**14.00-15.00** "Ask a Physiotherapist" – demonstration of exercises in response to questions.

**Patient Programme, Saturday 20 Feb**

**9.00-10.00** "Meet the Professor": Answers to your questions in your own language

in English, Room 3C *Prof. Maureen Mayes (USA) & Prof. Patricia Carriera (SP)* (translation into Portuguese, French, Spanish), Chair: A. Portales (SP)

in German, Room 3A **Prof. U. Müller-Ladner (D)**, Chair: G. Niehaus (D)

in Italian, Room 3B **Prof. M. Matucci-Cerinic (I)**, Chair: G. Tassini (I)

**10.00-11.00 What is Research doing for Me? What New Therapies can I try?**

- The Hope of Systemic Drugs **Prof. C. Denton (UK)**
- Considering Stem-Cell Transplants **Prof. J. Van Laar (NL)**
- My Lung Transplant **A. Martin (CH)**
- My Stem-Cell Transplant **R. Kanters (NL)**

Chairs: J. Welling (NL), Prof. A. Tyndall (CH)

11.00-11.30 *coffee break*

**11.30-12.00 After 10 years with SSc, What Can I Expect?**

- Predicting the Future with SSc **Dr. Jason Lee (CAN)**
- A Long Life With SSc **K. Fligelstone (UK)**

Chair: A. Roennow (Denmark) , Dr. Paulo Coelho (P)

**12.00-13.00 Coping: How can my family and I manage SSc better?**

- Dealing with Chronic Fatigue **Dr. J. Poole (USA)**
- Breathing Exercises **Dr. J. Poole (USA)**
- How to share SSc with a loved one **H. and I. Lever (Sweden)**
- Finding your way as a single mother: **M. Gaafar (CH)**
- A Meditation for stress relief: **Dr. L. A. Saketkoo (USA)**

Chair: A. Kennedy (IE), Dr. C. Resende (P)

**10.30-11.30, Parallel Session in Room 3B:** Wax Bath demonstrations **Dr. W. Gregory PT (UK)**

**11.30-12.30, Parallel Session in Room 3B:** Hand exercises **Dr. W. Gregory PT (UK)**

**10.00-11.00 and 11.00-12.00, Parallel Sessions in Room 3A** Screening of film "Beneath the Surface" **Christy McCaffrey (USA)**

**12.00-12.30, Parallel Session in Room 3A:** Nutrition in SSc (in Portuguese) **A. Cardoso (Portugal)**

Chair: H. Gaspar (Portugal)

**13.00 CLOSURE OF CONGRESS**

**13.30-15.30 FESCA MEETING OF ALL REPRESENTATIVES**

SIMULTANEOUS TRANSLATION OFFERED IN ROOM 3C

PATIENT POSTER DISPLAY AREA

FILM BY CHRISTY McCAFFREY (twice shown in Room 3A)