

# PATIENT PROGRAMME

## THURSDAY, FEBRUARY 15

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	<b>HOTEL IBIS LE LAC BORDEAUX MEETING ROOM</b>
15:00 17:00	<p><b>ROUND-TABLE NETWORKING MEETING FOR LEADERS OF PATIENT ASSOCIATIONS</b></p> <p>Theme:  <b>How to deal with psychological aspect of newly diagnosed patients?</b></p> <p>Facilitator: <b>Brett D. Thombs (CAN), Ph.D. Professor,</b>  Faculty of Medicine, McGill University</p> <p>20 min to present SPIN + opened discussions</p>
	<b>AUDITORIUM A - CONGRESS CENTER BORDEAUX</b>
18:00 21:30	<p>OPENING LECTURES AND WELCOME RECEPTION  FOR CLINICIANS AND PATIENTS</p>

Simultaneous translation in French and Spanish is provided in **Auditorium B** on Friday, February 16 and Saturday, February 17

## FRIDAY, FEBRUARY 16

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PATIENT PROGRAMME

	AUDITORIUM B	ROOM F1	ROOM E2	ROOM E1
9:00 9:05	FESCA Welcome by <b>President Annelise ROENNOW (DK)</b>			
9:05 9:30	<b>HAVE WE LEARNT NEW THINGS ABOUT SCLERODERMA?</b> Speaker: <b>Prof. Yannick ALLANORE (F)</b> 20 min + 5 min Q&A Chair: <b>Annelise ROENNOW (DK)</b> and <b>Prof. Dan FURST (USA)</b>			
9:30 10:00	<b>WHEN FIBROSIS STRIKES THE HEART OR LUNGS IN SSc</b> Speaker: <b>Dr. Roger HESSELSTRAND (S)</b> 20 min + 10 min Q&A Chair: <b>Monica HOLMNER (S)</b> and <b>DR Anne Braae OLESEN (DK)</b>	9:30-12:00 <b>Focus group: barriers and facilitators to physical activity in scleroderma (ENGLISH and FRENCH)</b>		
10:00 10:40	<b>MOUTHCARE AND DENTAL TREATMENTS FOR PATIENT WITH SEVERE SSc</b> Speaker: <b>Dr. Sophie JUNG (F)</b> - 20 min Patient experience: <b>Anna VEGH (H)</b> - 10 min Chair: <b>Stephan HOUBERTZ (D)</b> and <b>Dr. Voon ONG (UK)</b> Q&A - 10 min	<b>Dr. Brett THOMBS (CAN), Julie Cumin (CAN), Marie-Eve Carrier (CAN)</b>		10:00-11:00 <b>Posture and breathing exercises for SSc</b> <b>Jadranka BROZD, Sanja ROSKAR (HR)</b>
10:40 11:10	<b>COFFEE BREAK</b>			
11:10 11:40	<b>PLASTIC SURGERY: FACE/LIPS, SOLE, ETC. ANY DEVELOPMENT?</b> Speaker: <b>Dr. Louise PASQUESOONE (F)</b> 20 min + 10 min Q&A Chair: <b>Nadine PACIOTTI (CH)</b> and <b>Prof. Marco MATUCCI-CERINIC (I)</b>		11:00-11:50 <b>Chi Gong</b> Managed by <b>Gabi NIEHAUS (D)</b>	11:00-12:00 <b>Wax Bath</b> by <b>Will GREGORY (UK)</b>

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	AUDITORIUM B	ROOM F1	ROOM E2	ROOM E1
11:40 12:20	<p><b>SURGERY: SPECIFIC RECOMMENDATIONS FOR SSc PATIENTS</b>                      Speaker: <b>Prof. Luc MOUTHON (F)</b> - 15 min                      Patient experience: <b>Kim FLIGELSTONE (UK)</b> representing <b>Silvia SANDULESCU (RO)</b> - 5 min                      10 min Q&amp;A                      Chairs: <b>Beata GARAY-TOTH (H)</b>, <b>Dr. T. MINIER (H)</b></p>		<p>12:00-12:45  <b>How to prevent and treat digital ulcers</b>                      Managed by: <b>Michele TONDUT (F)</b> + <b>Dr. S. SKOPINSKI (F)</b></p>	<p>12:00-12:45  <b>Self face massage for SSc</b>  <b>Jadranka BROZD, Sanja ROSKAR (HR)</b></p>
12:20 12:50	<p><b>URINARY PROBLEMS</b>                      Speaker: <b>Dr. Gregor JOHN (CH)</b>                      20 min + 10 min Q&amp;A                      Chair: <b>Ann TYRRELL KENNEDY (IRL)</b> and <b>Prof. Dr. Miklós SARDY (H)</b></p>	<p>12:00-12:45  <b>Juvenile Scleroderma</b>                      Speaker: <b>Dr. Ivan FOELDVARI (D)</b>                      Patient experience: <b>Yun WAH (UK)</b></p>		
12.50 14:00	<b>LUNCH</b>			
14:00 15:00	<p><b>EDUCATIONAL THERAPY</b>                      Speakers: <b>Prof. Eric HACHULLA &amp; Dr. Joel CONSTANS (F) / S. JACQUEMET (CH)</b> - 15 min                      Patient experience: <b>Yanne COURCOUX (F)</b> - 5 min                      10 min Q&amp;A                      Chair: <b>Sue FARRINGTON (UK)</b></p>	<p>14:00-15:00  <b>Pregnancy</b>  <b>Dr. Silvia BREDA (I)</b>                      Chair: <b>Catarina LEITE (P)</b></p>	<p>14:00-15:00  <b>Sexual Life (Men session)</b>  <b>Toon Van HELMOND (NL)</b>, Health psychologist                      Chair: <b>Joep WELLING (NL)</b></p>	<p>14:00-14:50  <b>Chi Gong</b>                      Managed by <b>Gabi NIEHAUS (D)</b></p>
15:00 15:30	<p><b>HOW TO HANDLE UPPER/LOWER INTESTINAL TRACT PROBLEMS?</b>                      Speaker: <b>Prof. Dinesh KHANNA (USA)</b>                      20 min + 10 min Q&amp;A                      Chair: <b>Linda SCHRAVEN (NL)</b> and <b>Prof Laszlo CZIRJAK (H)</b></p>	<p>15:00-16:00  <b>Educational Therapy in French</b>                      Managed by <b>the Lille Medical team (F)</b>, <b>Dr Geraldine WOJTASIK</b> and <b>Dr Sandrine MORELL-DUBOIS (F)</b></p>	<p>15:00-16:00  <b>Sexual Life (Women session)</b>  <b>Elaine FURST, RN, BSN, MA (USA)</b>                      Chair: <b>Iliaria GALETTI (I)</b></p>	<p>15:00-16:00  <b>Wax Bath</b>                      by <b>Dr. William GREGORY (UK)</b></p>
15:30 16:00	<b>BREAK</b>			
16:00 17:00	<p><b>THE BENEFITS OF SOPHROLOGY IN SSc</b>                      Speaker: <b>Dr. Natalia CAYCEDO (E)</b>                      Speech + practice - 45 min                      Patient experience: <b>Martine TORRENT (F)</b> - 5 min                      10 min Q&amp;A                      Chair: <b>Dominique GODARD (F)</b></p>	<p>16:00-17:00  <b>Educational Therapy in English</b>                      Managed by <b>the Lille Medical team (F)</b>, <b>Dr Geraldine WOJTASIK</b> and <b>Dr Sandrine MORELL-DUBOIS (F)</b></p>	<p>16:00-17:00  <b>Making Tough Healthcare Decisions in Scleroderma: A Toolkit</b>                      Managed by <b>Dr. Brett THOMBS (CAN)</b></p>	<p>16:00-17:00  <b>Yoga for Body Strength, Vascular and Lung Health</b>  <b>Dr. Lesley Ann SAKETKÓO (USA)</b></p>

PATIENT PROGRAMME

## SATURDAY, FEBRUARY 17

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PATIENT PROGRAMME

	AUDITORIUM B	ROOM F1	ROOM E2
9:00 10:00	<b>MEET THE PROFESSOR</b> <b>Answers to your questions in ENGLISH</b> <b>Prof. Dan FURST (USA),</b> <b>Prof. Maureen MAYES (USA),</b> <b>Dr. Pia MOINZAHEH (D)</b>	<b>MEET THE PROFESSOR</b> <b>Answers to your questions in FRENCH</b> <b>Prof. Yannick ALLANORE (F),</b> <b>Prof. Eric HACHULLA (F)</b>	<b>MEET THE PROFESSOR</b> <b>Answers to your questions in GERMAN</b> <b>Prof. Dr. Miklós SÁRDY (H)</b>
10:00 10:45	<b>DEVELOPMENT OF NEW THERAPIES IN SSc</b> <ul style="list-style-type: none"> <li>• How to identify new therapies in the laboratory</li> <li>• New therapies for SSc: Update on ongoing clinical studies</li> </ul> <b>Prof. Dr. Jörg DISTLER (D)</b> - 15 min <b>Prof. Dr. Oliver DISTLER (CH)</b> - 20 min Chair: <b>Joep WELLING (NL)</b> Q&A - 10 min	10:00-11:00 <b>SOPHROLOGY IN SPANISH</b> Managed by <b>Martine TORRENT (F)</b>	10:00 am-01:00 pm <b>Focus group: barriers and facilitators to physical activity in scleroderma (ENGLISH and FRENCH)</b> <b>Dr. Brett THOMBS (CAN), Julie Cumin (CAN), Marie-Eve Carrier (CAN)</b>
10:45 11:15	<b>COFFEE BREAK</b>		
11:15 11:45	<b>TREATING PAIN IN DIGITAL ULCERS &amp; CALCINOSIS</b> Speaker: <b>Prof. Anne-Laure FAUCHAIS (F)</b> 20 min + 10 min Q&A Chair: <b>Kim FLIGELSTONE (UK)</b> and <b>Prof. Eric HACHULLA (F)</b>		
11:45 12:15	<b>RESEARCH ON KIDNEY FAILURE IN SSc</b> Speaker: <b>Prof. Chris DENTON (UK)</b> 20 min + 10 min Q&A Chair: <b>Despo CHARALAMBOUS (CY)</b> and <b>Dr. Carina MIHAI (RO)</b>	11:45-12:45 <b>SOPHROLOGY IN FRENCH</b> Managed by <b>Martine TORRENT (F)</b>	
12:15 12:45	<b>NUTRITION IN SSc</b> Speaker: <b>Dr. Lesley Ann SAKETKOO (USA)</b> 20 min + 10 min Q&A Chair: <b>Gabi NIEHAUS (D)</b>		

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	AUDITORIUM B	ROOM F1	ROOM E2
12:45 12:55	<b>SELF MANAGEMENT: OVERCOMING OBSTACLES IN EDUCATION AND WORK</b> Speaker: <b>Yun WAH (UK)</b> Chair: <b>Annelise ROENNOW (DK)</b>		
13:00	<b>CLOSING</b>		