

# PATIENT CONGRESS PROGRAMME

Patient congress will take place at the first floor of the Prague Congress Center. Simultaneous translation in Czech, Hungarian, German and Spanish is provided in Panorama Room on Friday, March 6 and Saturday, March 7

## THURSDAY, MARCH 5

	<b>ROOM CLUB A - FIRST FLOOR</b>
16:00 18:00	Roundtable for global patient-group leaders
	<b>FORUM HALL - SECOND FLOOR</b>
17:30 19:40	Opening Lectures for clinicians and patients
	<b>ZOOM ROOM - FIRST FLOOR</b>
19:45	Welcome Reception

## FRIDAY, MARCH 6

	PANORAMA ROOM	ROOM CLUB B	ROOM CLUB C	ROOM CLUB D
09:00 09:20	<p><b>WELCOME</b>  <b>Chair: Ann Kennedy (IE)</b>            Fesca Welcome - <b>Ann Kennedy (IE)</b> 5 min            Czech Association welcome - <b>Michaela Linková (CZ)</b> 5 min            What is new since 2018 and what can we expect for the next 2 years? - <b>Yannick Allanore (FR)</b> 10 min</p>			
09:20 09:55	<p><b>WHAT NEWLY DIAGNOSED PATIENTS MUST KNOW</b>  <b>Chairs: Marco Matucci-Cerinic (IT), Ann Kennedy (IE)</b>            Just diagnosed with scleroderma. Now what?  <b>Maureen Mayes (USA)</b> 15 min            How to deal with the news of the diagnosis  <b>Monika Červinková (CZ)</b> 10 min            Q&amp;A 10 min</p>			<p>09:20-10:30  <b>MINDFULNESS</b>            (in English)  <b>Gabi Niehaus (DE),</b>  <b>Alisa Niehaus (DE)</b></p>
09:55 10:30	<p>NEW TREATMENTS, RESEARCH AND EXPECTATIONS  <b>Chair: Joep Welling (NL)</b>            What are we learning from research? - <b>Chris Denton (UK)</b> 20 min            What patients should know about participation in clinical trials  <b>Joep Welling (NL)</b> 5 min            Q&amp;A 10 min</p>			
10:30 11:00	<b>COFFEE BREAK</b>			
11:00 11:50	<p><b>THE HANDS IN SCLERODERMA</b>  <b>Chairs: Beata Garay-Toth (HU), Gabriella Szucs (HU)</b>            Digital ulcers - <b>Michael Hughes (UK)</b> 15 min            Calcinosis - <b>Ariane Herrick (UK)</b> 10 min            How to keep hand mobility - <b>Linda Kwakkenbos (NL)</b> 10 min            Patient experience - <b>Merja Söderholm (FI)</b> 5 min            Patient experience - <b>Yanne Courcoux (FR)</b> 5 min            Q&amp;A - 5 min</p>	<p><b>MOUTH AND TEETH CARE</b>  <b>Yasmin Largiader (DE)</b></p>		<p>11:00-11:45  <b>BREATHING EXERCISES</b>  <b>Jadranka Brozd (HR),</b>  <b>Sanja Roskar (HU),</b>  <b>Adrian Brajković (HU)</b></p>

## FRIDAY, MARCH 6

	PANORAMA ROOM	ROOM CLUB B	ROOM CLUB C
11:50 12:25	<p><b>THE SKIN IN SCLERODERMA</b>  <b>Chairs: Gabi Niehaus (DE), Tunde Minier (HU)</b>                      Localised scleroderma - <b>Pia Moinzadeh (DE)</b> 10 min                      How systemic sclerosis affects the skin - <b>Pia Moinzadeh (DE)</b> 10 min                      Patient experience: what kind of problems should not be missed  <b>Kim Fligelstone (UK)</b> 5 min                      Q&amp;A 10 min</p>		
12:25 14:00	<b>LUNCH BREAK</b>		
14:00 15:10	<p><b>A GLOBAL APPROACH TO SYSTEMIC SCLEROSIS</b>  <b>Chairs: Kim Fligelstone(UK), Voon Ong (UK)</b>                      How to manage my life with Systemic Sclerosis optimally - <b>Eric Hachulla (FR)</b> 15 min                      Hyperbaric oxygen therapy - <b>Patricia Carreira (ES)</b> 10 min                      Occupational Therapy - <b>Hana Šmucrová (CZ)</b> 10 min                      Exercises for systemic sclerosis - <b>Maja Spiritovic (CZ)</b> 15 min                      Patient Support Programs from (SPIN) - <b>Brett Thombs (CA)</b> 10 min                      Q&amp;A 10 min</p>	<p>14:50-15:50  <b>WORKING TOGETHER IN DRUG DEVELOPMENT</b>                      Patient/Industry/Doctor Collaboration  <b>Ann Kennedy (IE), Oliver Distler (CH), Chris Denton (UK), Thomas Pfister (DE), Joep Welling (NL), Ilaria Galetti (IT), Ryan Van Goethem (DE)</b></p>	
15:10 15:30	<b>COFFEE BREAK</b>		
15:30 16:15	<p><b>GI TRACT</b>  <b>Chairs: Michael Oeschger (DE), Ulf Mueller-Ladner (DE)</b>                      Understanding the GI tract and gut problems  <b>Anna Maria Hoffmann-Vold (Norway)</b> 20 min                      Truths and lies on diets. How to maintain your weight  <b>Elizabeth Volkmann (USA)</b> 10 min                      Patient experience - <b>Joep Welling (NL)</b> 5 min                      Q&amp;A 10 min</p>		<p><b>SUPPORTING CARERS</b>  <b>Vanessa Malcarne (USA), Juan Holmner (SE)</b></p>
16:15 16:40	<p><b>URINARY PROBLEMS</b>  <b>Chairs: Ann Kennedy (IE), Janet Pope (CA)</b>                      Urinary problems - <b>Gregor John (CH)</b> 15 min                      Patient experience - <b>Silvia Sandulescu (RO)</b> 5 min                      Q&amp;A 5 min</p>		<p>16:15-17:30  <b>MINDFULNESS</b>                      (in German)  <b>Gabi Niehaus (DE), Alisa Niehaus (DE)</b></p>
16:40 17:40	<p><b>FAMILIES WITH CHILDREN WITH SSC. HOW TO COPE</b>  <b>Chairs: Kim Fligelstone (UK), Linda Schraven (NL)</b>                      Paediatric Scleroderma- <b>Ivan Foeldvari (HU)</b> 20 min                      Parents' experience - <b>Teresa &amp; Rebecca Pizzetti (IT)</b> 10 min                      Patient experience with systemic - <b>Anna &amp; Jana Pařízková (CZ)</b> 10 min                      Patient experience from childhood - <b>Silvia Sandulescu (RU)</b> 10 min                      Patient experience with localised - <b>Iva Bendlová (CZ)</b> 10 min</p>		

## SATURDAY, MARCH 7

	PANORAMA ROOM	ROOM CLUB B	ROOM CLUB C	ROOM CLUB D
09:00 09:45	<b>TRANSPLANTS</b> <b>Chair: Linda Schraven (NL)</b> Who could benefit from a transplant? <b>Jaap van Laar (NL)</b> 10 min Reducing toxicity in transplants - <b>Alan Tyndall (CH)</b> 15 min Patient experience - <b>Michael Oeschger (DE)</b> 10 min Q&A - 10 min			
09:45 10:35	<b>ASK THE PROFESSOR</b> In English <b>Marco Mattedi-Cerinic (IT), I Castellvi (ES)</b>	<b>ASK THE PROFESSOR</b> In French <b>Yannick Allanore (FR)</b>	<b>ASK THE PROFESSOR</b> In Hungarian <b>Laszlo Czirjak (HU)</b>	<b>ASK THE PROFESSOR</b> In German <b>Ulf Mueller-Ladner (DE)</b>
10:35 11:00	<b>COFFEE BREAK</b>			
10:45 11:45	<b>GROWING UP WITH SSC: ADULTS UP TO 30 YEARS</b> <b>Chairs: Kim Fligelstone (UK), Linda Schraven (NL)</b> Adults with juvenile scleroderma <b>Marina Anderson (UK)</b> 20 min Patient Experience <b>Alison Zheng (CN)</b> 10 min A whole life with scleroderma <b>Linda Kwakkenbos (NL)</b> 20 min Workshop Q&A - <b>Catarina Leite (PT)</b> 10 min	11:00-11:45 <b>SEXUALITY FOR MEN</b> <b>Michael Oeschger (DE), Stephan Houbertz (DE), Joep Welling (NL), Juan Holmner (SE)</b>	11:00-11:45 <b>SEXUALITY FOR WOMEN</b> <b>Tanaka Ngcozana (UK), Catarina Leite (PT), Monica Holmner (SE)</b>	11:00-11:45 <b>BREATHING EXERCISES</b> <b>Jadranka Brozd (HR), Sanja Roskar (HU), Adrian Brajković (HU)</b>
11:45 12:45	<b>LUNGS AND HEART</b> <b>Chairs: Ilaria Galetti (IT), Francesco Del Galdo (UK)</b> Interstitial Lung Disease - <b>Oliver Distler (CH)</b> 20 min PAH-the heart in SSc - <b>Carina Mihai (CH)</b> 20 min Patient experience, lungs - <b>Edith Brown (UK)</b> 10 min Q&A - 10 min		11:50-12:45 <b>PREGNANCY</b> <b>Tanaka Ngcozana (UK), Catarina Leite (PT), Maia Spiritovic (CZ)</b>	
12:45 13:00	<b>CLOSURE WITH TAKEAWAY MESSAGES</b> <b>Ann Kennedy (IE), Alan Tyndall (CH)</b>			
13:00	<b>FAREWELL PARTY</b> (tapas and beverages)			