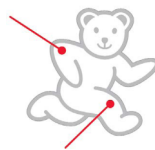


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Organized in cooperation with the **Hamburger Zentrum für Studien und Fortbildung in der Kinder- und
Jugendrheumatologie gGmbH**
Preliminary program



19th Hamburg Symposium on Juvenile Sclerosis

– Update on New Developments –

How do we define “damage” in juvenile systemic sclerosis patients?

Date: December 05th 2026, 10.00-18.00

Location: Schön Klinik Eilbek, Haus 7., Dehnhaiide 120, 22081 Hamburg, Germany

Programme

10.-10.10 Introduction – Ivan Foeldvari

How do we define “damage” in systemic sclerosis? Lessons from adult cohorts?

Chairman: Vanessa Smith and Ivan Foeldvari

10.10-10.35 The SCTC damage index. Laura Ross/ Wendy Stevens; Melbourne, Australia

10.35- 10.55– How do we define cumulative disease damage in SSc? John Pauling

10.55.-11.15 Evaluating SSc damage indices in the EUSTAR cohort. Francesco del Galdo

11.15-11.35 Validation of the SCTC damage instrument in the Toronto Scleroderma Program cohort.
Sindhu Johnson (Adult Rheumatologist, Toronto Scleroderma Program, University of Toronto)

11.35-11.55 Defining at-risk patients for preventive trials in systemic sclerosis across stage and
subset. Chris Denton, Division of Medicine, University College London, London, UK

11.35- 11-50 Roundtable - Question & Answers

11.50.-12.10 Coffee break

How is the SCTC damage index works in the paediatric cohort?

Chairman: Chris Denton and Clarissa Pilkington

12.10-12.30 Is the SCTC damage index a valid instrument in the juvenile systemic sclerosis inception cohort. - Jens Klotsche /Ivan Foeldvari

12.30.-12.50 Is the SCTC damage index a valid instrument in the National Registry of Childhood onset systemic Sclerosis - Cassie Torok /Jon Li

12.50.-13.10 Roundtable - Question & Answers

13.10-14.00 Lunch Break

14.00 -18.00 Proposal of the working groups:

How do we define damage in juvenile systemic sclerosis patients?

Report of the working groups and associated talks: All speakers are presenting bullet points and key questions to the group at the end of their talk. Each talk can be up to 20 minutes and 10 minutes discussion

Chairman: Clare Pain and Maurizio Cutolo

14.00.-16.00 Proposal of the working groups:

- i. Cutaneous involvement – **Catherine Orteu**, Ivan Foeldvari, Cassie Torok
- ii. Musculoskeletal Involvement –**Suzanne Li** and Jordi Anton
- iii. Interstitial lung disease – **Franziska Roser, Jon Li** ; Cassie Torok, Ivan Foeldvari and Bernd Hindrichs

16.00- 16.20 Coffee Break

Chairman Suzanne Li and John Pauling

16.20-18.15 Proposal of the working groups:

- i. Cardiac involvement and pulmonary hypertension–**Eduardo Marrani**, Clarissa Pilkington, Peer Hauck,
- ii. Raynauds and vascular involvement – **Clare Pain**
- iii. Renal involvement - **Patricia Costa Reis**
- iv. Gastrointestinal Involvement – **Cassie Torok**

18.15-18.25 Closing Remarks: Ivan Foeldvari

The symposium is supported by an unrestricted funds by :

2 . Day of the Meeting 6th of December 2026

Location: Schön Klinik Eilbek, Haus 2, Dehnhaide 120, 22081 Hamburg, Germany

09.00- 16.00 Consensus meeting -

How do we define “damage” in juvenile systemic sclerosis?

Principal Investigator:

Ivan Foeldvari (Paediatric Rheumatologist, Hamburger Zentrum für Kinder- und Jugendrheumatologie, Hamburg, Germany)

Moderator:

- Vanessa Smith Vanessa Smith (Adult Rheumatologist) Department of Rheumatology, Ghent University Hospital, Ghent, Belgium);

Planned Participants :

- Cosimo Bruni, (Adult Rheumatologist, University Zurich, Switzerland)
- Maurizio Cutolo (Adult Rheumatologist, Department of Rheumatology University Genua, Italy),
- Chris Denton (Adult Rheumatologist, Royal Free Hospital, London, UK),
- Ivan Foeldvari (Pediatric Rheumatologist, Hamburger Zentrum für Kinder- und Jugendrheumatologie),
- Kim Fligelstone (Patient Representative, FESCA),
- Francesco del Galdo, (Adult Rheumatologist, University Leeds ; UK)
- Peer Hauck (Pediatric Cardiologist, Hamburg),
- Jörg Henes (Adult Rheumatologist, University Tübingen, Germany)
- Sindhu Johnson (Adult Rheumatologist, University of Toronto, Canada)
- Ozgur Kasapcopur, (Pediatric Rheumatologist, Istanbul, Turkey)
- Jon Li (Pediatric Rheumatologist, University Children's Hospital Pittsburgh, USA),
- Susan Maillard (Pediatric Physio Therapist, GOH, London, UK)
- Eduardo Marrani (Pediatric Rheumatologist, Florence, Italy),
- Giorgia Martini, Pediatric Rheumatologist, Udine, Italy
- Suzanne Li (Pediatric Rheumatologist, Hackensack University, New Jersey, USA)
- Catherine Orteu (Dermatologist, UCL, London, UK),
- Clare Pain (Pediatric Rheumatologist, Liverpool UK)
- John Pauling (Adult Rheumatologist, Bath, UK)

- Clarissa Pilkington, (Pediatric Rheumatologist, Great Ormond Street Hospital, London , UK),
- *Patricia Costa Reiss (Pediatric Rheumatologist and Nephrologist, Hospital de Santa Maria, Lisbon, Portugal)*
- Franziska Roser (Pediatric Pulmonologist, University Children's Hospital Pittsburgh, USA)
- *Catarina Leite (Patient Representative, FESCA);*
- Laure Ross/ Wendy Stevens (Adult Rheumatologis, Melbourne)
- Cassie Torok (Paediatric Rheumatologist, University Children's Hospital Pittsburgh, USA)
- Bernd Hinrichs