

May 28th-29th 2021 Medical University Innsbruck, Austria

Connective Tissue, Immune System & Rare Ehlers Danlos Syndromes

The pathogenesis of disease features in the Ehlers Danlos syndromes (EDS) and the reasons for variable clinical presentations are only partly understood. The symposium will discuss current knowledge on the production, assembly and regulation of extracellular matrix components and its links to the immune system, as well as normal and abnormal functions in genetically defined rare types of EDS. Aim is the identification of research questions and the establishment of collaborative networks to investigate disease mechanisms of connective tissue disorders. The meeting is intended as a series of conversations by a small group of professionals rather than a succession of lectures in order to foster creativity and stimulate lively discussions.

In view of the COVID-19 travel restrictions, the symposium is primarily an online meeting.

1. International research symposium:

Connective Tissue, Immune System & Rare Ehlers Danlos Syndromes

Friday afternoon 12:50-19:30

12:50	<i>Welcome</i>	Johannes Zschocke & Fransiska Malfait
13:00-13:30	Current topics in rare EDS	Peter Byers, Seattle
13:30-14:00	Collagen processing: current knowledge	Florence Ruggiero, Lyon
14:00-14:30	Proteoglycan synthesis and EDS	Tomoki Kosho, Matsumoto
14:30-15:00	<i>Coffee/Tea Break</i>	
15:00-15:30	Extracellular vesicles and the ECM	Daniel W. Lambert, Sheffield
15:30-16:00	Dysregulation of the ECM	Karl Kadler, Manchester
16:00-16:30	Unfolded protein response and degradation	Tom van Agtmael, Glasgow
16:30-17:00	<i>Coffee/Tea Break</i>	
17:00-17:30	ECM and the immune system	Lydia Sorokin, Münster
17:30-17:45	Complement 1 proteases and EDS	Christine Gaboriaud, Grenoble
17:45-18:15	Non-canonical functions of C1 subunits	Lubka Roumenina, Paris
18:15-18:45	Immunological functions of the C1 complex	Marina Botto, London
18:45-19:30	Round table: Rare EDS, ECM and the immune system	

2. European networking meeting: Challenges of EDS research and care

Saturday morning 9:00- 13:30:

9:00-9:20	Mouse model of chronic pain in EDS	Delfien Syx, Ghent
9:20-9:40	Zebrafish models for EDS	Paul Coucke, Ghent
9:45-11:00	EDS in Europe: insights and experiences	Various stakeholders
11:00-11:30	<i>Coffee Break</i>	
11:30-12:00	What can ERNs offer to the EDS community?	Representatives of different ERNs (ReConnet, Skin, VascERN) (tbc.)
12:00-13:00	Discussion, plans, summary	Fransiska Malfait, Ghent (chair)
13:00	<i>End of scientific / networking meeting</i>	

3. Update on the rare EDS types

Saturday afternoon 15:00-21:00

Educational presentations organized by the EDS Society.

- Pre-recorded presentations (10-20 min) with a Q&A session (5-10 min) after each talk
- Presentations are suitable for EDS community, their families, caregivers and healthcare professionals.
- Languages (live translation): English (original language), French, German, Spanish, Japanese

15:00-15:15	General introduction (EDS, differential diagnosis of all EDS types)	Fransiska Malfait, Ghent
15:15-15:45	Strategies and pitfalls of molecular analyses in EDS	Johannes Zschocke, Innsbruck

20+10 min	Classical-like EDS (clEDS) & new types	Serwet Demirdas, Rotterdam
20+10 min	EDS and collagen 1; incl. cardiac-valvular EDS (cvEDS), arthrochalasia EDS (aEDS)	Anthony Vandersteen, Halifax
10+5 min	Dermatosparaxis EDS (dEDS)	Fransiska Malfait, Ghent
20+10 min	Brittle Cornea Syndrome (BCS) Kyphoscoliotic EDS (kEDS)	Marianne Rohrbach, Zürich
13+7 min	Spondylodysplastic EDS (spEDS)	Roberto Mendoza, London
13+7 min	Musculocontractural EDS (mcEDS)	Tomoki Kosho, Matsumoto
13+7 min	Myopathic EDS (mEDS)	Fleur Van Dijk, London
20+10 min	Orodonal manifestations of EDS, periodontal EDS (pEDS)	Ines Kapferer-Seebacher, Innsbruck Ulrike Lepperdinger, Innsbruck
3x7 min	Rare EDS: view from the inside 3x10 Min messages	

2x 30 min	<i>Coffee/Tea break</i>	
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20:30-21:00	Rare EDS issues: cohort studies, future developments, general topics, EDS society, patient organisations	All speakers Chair: Fransiska Malfait, Ghent
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Speakers are asked to suggest 7 min patient presentations for their topics; a maximum of 3 presentations will be distributed in the schedule.

Scientific Organizing Committee:

Rebekka Gröbner, Innsbruck, Ines Kapferer-Seebacher, Innsbruck, Fransiska Malfait, Gent, Fleur van Dijk, London, Johannes Zschocke, Innsbruck

Participants:

Members of the EDS Rarer Types Committee:

- Serwet Demirdas
- Fleur Van Dijk
- Roberto Mendoza-London
- Tomoki Kosho
- Anthony Vandersteen
- Sylvie Fournel-Gigleux
- Cecilia Giunta
- Neeti Ghali
- Marianne Rohrbach
- Ines Kapferer-Seebacher
- Claire Green
- Johannes Zschocke

Speakers:

- Marina Botto, London
- Peter Byers, Seattle
- Paul Coucke, Ghent
- Serwet Demirdas, Rotterdam
- Christine Gaboriaud, Grenoble
- Karl Kadler, Manchester
- Ines Kapferer-Seebacher, Innsbruck
- Tomoki Kosho, Matsumoto
- Daniel W. Lambert, Sheffield
- Ulrike Lepperdinger, Innsbruck
- Fransiska Malfait, Ghent
- Roberto Mendoza, London
- Marianne Rohrbach, Zürich
- Florence Ruggiero, Lyon
- Lydia Sorokin, Münster
- Delfien Syx, Ghent
- Tom van Agtmael, Glasgow
- Anthony Vandersteen, Halifax
- Lubka Roumenina, Paris
- Fleur van Dijk, London
- Johannes Zschocke, Innsbruck