



It is with great pleasure that we invite you to participate in the

International Symposium on the Ehlers-Danlos Syndromes

September 26–29, 2018

The conference will take place in beautiful **Ghent, Belgium**, “Belgium’s best kept secret” (according to the *Lonely Planet*).

The International Symposium on the Ehlers-Danlos Syndromes (EDS) is a state-of-the-art meeting in which new research on clinical advances and the molecular and pathogenic mechanisms underlying EDS and related syndromes is discussed. We offer a high quality scientific program with the general theme: “**Interaction and signaling: recurrent themes in the molecular mechanisms of EDS.**” The meeting brings together an international panel of clinicians, clinical and basic scientists and representatives of patients support groups to foster constructive discussions and multidisciplinary debates that focus on the multiple aspects of the Ehlers-Danlos syndromes and associated pathologies. These include the molecular etiology of these disorders, the biochemical abnormalities produced by the underlying mutations affecting genes involved in connective tissue homeostasis, the clinical consequences of these mutations, the latest advances in therapies and management (medical, surgical and physiotherapeutic) and the effects of these interventions on the natural history of the disease.

We strongly encourage clinicians and researchers with an interest in the Ehlers-Danlos syndromes to attend this meeting. We expect 250 delegates and key opinion leaders in the field from around the world to attend. The **multidisciplinary** nature of the conference provides an opportunity to talk to specialists from many different fields including basic scientists, geneticists, internists, orthopedic and vascular surgeons, dentists, pediatricians, physiotherapists, genetic counselors, nurses, representatives of patient support groups, and many others working with Ehlers-Danlos syndromes.



International Symposium on the Ehlers-Danlos Syndromes

Interaction and signaling: recurrent themes in the molecular mechanisms of EDS

26–29 September 2018, Ghent, Belgium

Highlights include:

- An exciting program of invited speakers and lectures featuring some of the leading experts in the field
- Presentation of talks chosen from submitted abstracts
- A workshop for physiotherapists
- A well-attended poster session with local gastronomic treats
- A Social Program in the historic center of Ghent: a welcome reception, a boat trip on the rivers and canals of Ghent, and a Gala Dinner with party.
- An exhibition area

To qualify for early registration rates, you must register by July 15, 2018.

(<https://www.ehlers-danlos.com/2018-eds-ghent/2018-eds-ghent-registration/>)

When and Where?

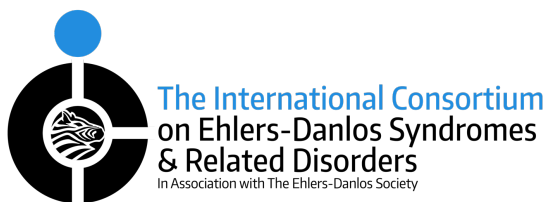
26-29 September 2018

De Oude Vismijn
Sint-Veerleplein 5
9000 Ghent, Belgium

<https://www.ehlers-danlos.com/2018-eds-ghent/>

We hope that you will join us for an exciting meeting with constructive and amiable discussions about state-of-the-art clinical and basic science related to the Ehlers-Danlos syndromes. Come and participate in an interactive meeting in beautiful Ghent!

Organized in association with





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Preliminary Program-Outline of the Conference

Wednesday, 26 September

14:00 – 14:30	Welcome address
14:30 – 17:00	Session I: Collagen biosynthesis and EDS Collagen biosynthesis, folding, modification and secretion <i>Hans Peter Bächinger, Shriners Hospital for Children, Portland, USA</i> Presentations selected from abstract submissions
17:00 – 17:45	Keynote Lecture Clock genes and connective tissue protein regulation <i>Karl Kadler, University of Manchester, UK</i>
18:00 – 20:00	Welcome Reception

Thursday, 27 September

8:30 – 12:00	Session II: Type V collagen and EDS Three decades of research on type V collagen: what have we learned? <i>Daniël Greenspan, University of Wisconsin, USA</i> Presentations selected from abstract submissions
12:00 – 14:30	Lunch Break/Posters/Exhibits
14:30 – 18:00	Session III: Hypermobile EDS and Hypermobility Spectrum Disorders Identifying genetic defects in hypermobile EDS and HSD <i>Joel Hirschhorn, Broad Institute, Harvard Medical School, Boston, USA</i> Studying chronic pain in murine models for EDS <i>Anne-Marie Malfait, Rush Medical School, Chicago, USA</i> EDS and the autonomic nervous system <i>John Oakley, University of Washington, Seattle, USA</i> Presentations selected from abstract submissions
18:00-20:00	Poster Session

Friday, 28 September

	<p>Session IV: Type III collagen and EDS</p> <p>Presentations selected from abstract submissions</p>
12:00 – 13:00	Lunch Break/Posters/Exhibits
13:00 – 15:00	<p>Session V: Rare EDS subtypes I</p> <p>FKBP22 and its role in the pathogenesis of EDS <i>Yoshi Ishikawa, Shriners Hospital for Children, Portland, USA</i></p> <p>P3h3-null and Sc65-null Mice Phenocopy the Collagen Lysine Under-hydroxylation and Cross-linking Abnormality of kyphoscoliotic EDS <i>Roy Morello, University of Medical Sciences, Arkansas, USA</i></p> <p>Presentations selected from abstract submissions</p>
15:00 – 15:30	Coffee Break
15:30 – 17:30	<p>Session VI: Rare EDS subtypes II</p> <p>Periodontal EDS and the Complement Pathway <i>Johannes Zschocke, Medical University Innsbruck, Austria</i></p> <p>Zebrafish models for collagen-related diseases: what can they learn us? <i>Florence Ruggiero, University of Lyon, France</i></p> <p>Presentations selected from abstract submissions</p>
19:00 – 00:00	Gala Dinner

Saturday, 29 September

9:00 – 12:00	<p>Session VII: Unmet needs and Future directions in EDS Research</p> <p>Presentations selected from abstract submissions</p>
12:00 – 12:30	Closing Remarks
13:30 – 17:30	Physiotherapy workshop

Abstracts on all aspects of basic, clinical, surveillance and management research in EDS are welcomed. A substantial number of submitted abstracts will be selected for platform presentation, the remainder of selected abstracts will be presented during an interactive poster session.

Suggested topics:

1. Molecular pathogenesis of EDS and related disorders

What is the spectrum of genetic defects underlying the different forms of EDS? Have novel genes been identified since the 2017 EDS classification? What cellular events and signaling pathways drive the different manifestation of EDS, e.g. wound healing, chronic pain, joint hypermobility, arterial fragility, ocular manifestations? How do they cross-talk with each other? Can we identify attractive treatment targets?

2. Genotype/Phenotype Correlations in EDS

What new insights regarding phenotype-genotype correlations have emerged? Are they useful to guide prognostication, surveillance, preventive or treatment strategies? What are the clinical and genetic database/registry needs of the global community?

3. Lessons learned from EDS animal models

What have we learned from existing animal models for EDS? What are the strengths and weaknesses of these models? Which murine models are needed to advance research in different types of EDS? How can zebrafish and other non-murine animal models advance research in EDS?

4. Natural History and disease manifestations of EDS and HSD

What have we learned from natural history studies in the different forms of EDS and hypermobility syndromes? What are the risks associated with pregnancy and delivery for the different EDS subtypes? What have we learned from clinical practice on long-term outcomes in the different types of EDS?

5. Genetic and Environmental Modifiers of EDS - Phenotypic Variability

What is the nature of genetic modifiers that influence phenotypic outcome in EDS? What is the influence of gender, pregnancy and lactation on disease severity in EDS and HSD? Which environmental factors (e.g. exercise, circadian rhythm, exposures...) determine outcome?

6. Insights Regarding Vascular Manifestations in the different types of EDS and in HSD

What is the risk for life-threatening vascular manifestations in the different types of EDS? What are recommendations for surveillance and (surgical) treatment of these vascular complications? What have we learned from clinical practice? Have there been advances in identifying biomarkers that can predict arterial rupture in EDS patients?

7. Insights regarding co-morbidities in the different types of EDS and HSD

What is the prevalence of the different comorbidities in the different types of EDS and in HSD (dysautonomia, mast cell activation syndrome, chronic fatigue, POTS, gastro-intestinal comorbidities, anxiety, depression etc)? What is the evidence for a causal relation between the different comorbidities and the underlying genetic defects? What are management strategies for these co-morbidities?

8. Insights regarding pain in EDS and HSD

What do we know about the nature and the pathogenesis of pain in EDS and HSD? How can animal models advance pain research in EDS and HSD? What is the role of medical and physical therapy in pain management and quality of life? What is the role of holistic treatment modalities in pain management? What are the current approaches to treatment of musculo- and non-musculoskeletal pain in EDS and HSD?

9. Psycho-social aspects of EDS

Are there barriers to care for people with EDS? How do they manifest and what are the consequences? What are the major contributing factors? Is there a unique social/psychological profile of people with each type of EDS?