



The **Ehlers-Danlos** Society

Precision Medicine for Genetically Defined Ehlers-Danlos Syndromes:

Genetic and Allelic Variation in Decision-Making About Diagnosis, Natural History, and Treatment

AGENDA



September 3-4, 2026



This is a Hybrid Event: In Person
and Virtual Attendance



The **Ehlers-Danlos** Society

Precision Medicine for Genetically Defined Ehlers-Danlos Syndromes:

Genetic and Allelic Variation in Decision-Making About Diagnosis, Natural History, and Treatment

Meeting Overview

This focused research meeting brings together experts to explore three key themes:

- How genetic analysis of the genes involved in the genetically defined types of Ehlers-Danlos syndrome (EDS) can predict natural history
- How it can stratify care
- How genetic information can identify routes to therapy that might include gene replacement, gene modification, activation of modifying pathways through small molecule intervention, and protein replacement.

What Participants Will Gain

- Insight into the role of genetics in predicting disease progression
- Understanding of how genomic data can inform personalized care strategies
- Awareness of emerging therapeutic approaches and translational opportunities
- Opportunities to engage with experts and build interdisciplinary collaborations



THURSDAY SEPTEMBER 3: SETTING THE STAGE

TIME (EST):	SESSION & PRESENTATION:	SPEAKER(S):
08:45-08.55	Welcome address (Peter Byers, Fransiska Malfait, Lara Bloom)	
Session 1: Classical EDS (cEDS) – COL5A1, COL5A2		
08.55-10.30	Welcome to Session 1	Fransiska Malfait
	Phenotype and natural history of cEDS: COL5A1 haploinsufficiency vs dominant negative variants	TBA
	Mechanisms of pathogenesis and variations in expression level of different alleles	TBA
	Distinction between COL5A2- and COL5A1 related phenotypes	Fransiska Malfait
	Vascular disease in cEDS	Karelle Benistan Serwet Demirdas
SELECTED SHORT AND FLASH PRESENTATIONS FROM ABSTRACTS - TBA		
REFRESHMENT BREAK & NETWORKING		
Session 2: Vascular EDS (vEDS) - COL3A1		
10.45-12.30	Welcome to Session 2	Peter Byers
	Genetically defined “natural history”- haploinsufficiency as a model for variant allele inactivation	TBA
	How correct are life span predictions - what are the issues and how does that identify targets for therapy	Bruce Gelb
	Stratification of care based on variant identity, and what about helical non-glycine substitutions (including Glu>Lys) and propeptide variants	Michael Frank Bart Loeys
	Splice variants and approaches to therapy	Ulrike Schwarze
	What can we learn from parental mosaicism - no need to target all cells, but how many?	Peter Byers Xavier Jeunemaitre
	Who to treat and when to start treatment?	Xavier Jeunemaitre
	Variants and pregnancy related complications in vEDS	TBA
	Modifiers of vascular events: of mice and man	Hal Dietz
	Biallelic variants and therapy	TBA
SELECTED SHORT AND FLASH PRESENTATIONS FROM ABSTRACTS - TBA		
10.45-12.30	Round Table Discussion	All Speakers
12:30-13:30 - LUNCH BREAK & NETWORKING		



SESSION



ABSTRACTS



BREAK

Please note: since this is a live event, times are approximate & are subject to change. If you miss anything live, you can catch up by watching the recordings back.

THURSDAY SEPTEMBER 3: SETTING THE STAGE

TIME (EST):	SESSION & PRESENTATION:	SPEAKER(S):
Session 3: Kyphoscoliotic (kEDS) – PLOD1, FKBP14		
13:30-14:30	Welcome to Session 3	TBA
	Clinical and allelic spectrum (Differences between the duplication event, missense, and nonsense variants)	TBA
	Vascular complications in kEDS	Caroline Michot Marianne Rohrbach
	When to treat, what to follow?	Michael Frank
	Protein targeting to the ER for PLOD1?	TBA
SELECTED SHORT AND FLASH PRESENTATIONS FROM ABSTRACTS - TBA		
Session 4: Arthrochalasi EDS (αEDS) – COL1A1, COL1A2		
14:30-15:15	Welcome to Session 4	TBA
	Can insights gained from mechanistic studies offer opportunities for small molecule therapy/gene therapy?	TBA
SELECTED SHORT AND FLASH PRESENTATIONS FROM ABSTRACTS - TBA		
REFRESHMENT BREAK & NETWORKING		
Session 5: Dermatosparaxis EDS (dEDS) – ADAMTS2		
15:30-16:15	Welcome to Session 5	TBA
	Key Topics - Variation in phenotype with genotype - Treatment strategies	TBA
SELECTED SHORT AND FLASH PRESENTATIONS FROM ABSTRACTS - TBA		
REFRESHMENT BREAK & NETWORKING		
Session 6: Other EDS types		
16:15-17:00	Welcome to Session 6	TBA
	Can insights gained from mechanistic studies offer opportunities for small molecule therapy/gene therapy?	TBA



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THURSDAY SEPTEMBER 3: SETTING THE STAGE

TIME (EST):	SESSION & PRESENTATION:	SPEAKER(S):
SELECTED SHORT AND FLASH PRESENTATIONS FROM ABSTRACTS - TBA		
CLOSING THOUGHTS		

FRIDAY SEPTEMBER 4: ACT I

TIME (EST):	SESSION & PRESENTATION:	SPEAKER(S):
08:50-09:00	Welcome address	
Session 1: vEDS: current practice		
09:00-10:00	Welcome to Session 1	TBA
	Stratification in obstetric care	Alexandra Benachi
	Small molecule therapy in vEDS — antihypertensives and other small molecules in humans and mouse models	Hal Dietz Xavier Jeunemaitre Bart Loeys ww
SELECTED SHORT AND FLASH PRESENTATIONS FROM ABSTRACTS - TBA		
Session 2: Insights gained from other diseases & An introduction to gene therapy		
10:00-12:30	Welcome to Session 2	TBA
	Osteogenesis imperfecta as a model system	Antonella Forlino Dimitra Micha
	Gene therapy: an introduction	Frauke Coppieters
	Genetic eye disease as a model system	Bart Peter Leroy
REFRESHMENT BREAK & NETWORKING		
10:00-12:30	Genodermatoses as model system	Mark Osborn Alexander Nyström
	Gene therapy in collagen disorders	Klaudia Kocsy
	Making and fixing haploinsufficiency	TBA
12:30-13:30 - LUNCH BREAK & NETWORKING		



SESSION



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FRIDAY SEPTEMBER 4: ACT II

TIME (EST):	SESSION & PRESENTATION:	SPEAKER(S):
Session 3: What have we learned from pathomechanistic insights to treat EDS symptoms?		
13:30-15:00	Welcome to Session 3	TBA
	Would healing and type V collagen	Arjun Deb
	Pain and type V collagen	TBA
	Topics TBD	TBA
SELECTED SHORT AND FLASH PRESENTATIONS FROM ABSTRACTS - TBA		
REFRESHMENT BREAK & NETWORKING		
Session 4: Title TBD		
15:30-16:30	Welcome to Session 4	TBA
	EDS Society Biobank for monogenic EDS	Alan Hakim TBA
	Title TBD	TBA
	Title TBD	Industry
	Title TBD	TBA
CLOSING THOUGHTS AND FAREWELL		



SESSION



ABSTRACTS



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