



The  
Ehlers  
Danlos  
Society

# GENETICALLY DEFINED EDS:

## Strategies & Solutions for Unmet Needs

AUGUST 30-31, 2023

**BELGIUM**



### AGENDA

## COMMUNITY SESSION

OPEN TO COMMUNITY MEMBERS

**THURSDAY AUGUST 31, 2023**

TIME (CEST) :	PRESENTATION	SPEAKER(S)	AFFILIATIONS
13:30 - 13:50	Unmet Needs and Challenges for Patients and Families Living with Genetically Defined Types of EDS: Results From A European Survey	Charissa Frank, Eva Collado	Eva Collado: ePAG ReCONNET Charissa Frank: ePAG ReCONNET
13:50 - 14:50	Organization of Care for Patients Living With Genetically Defined Types of EDS: Centers of Expertise & Care Teams	Glenda Sobey, Fleur van Dijk, Fransiska Malfait, Karelle Bénistan, Lara Jorge, Serwet Demirdas, Marijn Vis, Sherene Shalhub, Peter Byers, Clair Francomano	Glenda Sobey: UK Ehlers-Danlos Syndrome National Diagnostic Service, Sheffield Children's NHS, UK Fleur van Dijk: Northwick Park Hospital, London, UK Fransiska Malfait: Ghent University Hospital, Belgium Karelle Bénistan: Hôpital Raymond-Poincaré – Hôpitaux universitaires Paris Ile-de-France Ouest, France Lara Jorge: Hôpital Raymond-Poincaré – Hôpitaux universitaires Paris Ile-de-France Ouest, France Serwet Demirdas: Department of Clinical Genetics, Erasmus MC, University Medical Center Rotterdam, Rotterdam, The Netherlands Marijn Vis - Department of Rheumatology, Erasmus Medical Center, Rotterdam, The Netherlands Peter Byers: Pathology at University of Washington Medical Center, Seattle, USA
14:50 - 15:05	Cardiovascular Manifestations and Follow-up in Adults	Michael Frank	AP-HP, Hôpital Européen Georges Pompidou, Paris, France
15:05 - 15:20	Cardiovascular Manifestations and Follow-up in Children	Laura Muino-Mosquera	
15:20 - 15:30	Panel Discussion	Laura Muino-Mosquera, Michael Frank	
<b>BREAK: 15:30 - 15:45</b>			
15:45 - 16:30	Handle with Care! Physical Therapy For Genetically Defined Types of EDS	Lies Rombaut, Inge De Wandele, Nina Riise, Thy Thy Vanem, Marianne Mørk	Lies Rombaut: Ghent University Hospital, Ghent, Belgium Inge De Wandele: Ghent University Hospital, Ghent, Belgium Nina Riise: TRS, National Resource Centre for Rare Disorders, Sunnaas Rehabilitation Hospital, Nesoddtangen, Norway Thy Thy Vanem: Oslo University Hospital, Oslo, Norway Marianne Mørk: Oslo University Hospital, Oslo, Norway
16:30 - 16:45	Q&A		
16:45 - 16:55	Community Voice	Clare Stacey	
16:55 - 17:15	Psychosocial Aspects of Living with a Genetically Defined Type of EDS	Jess Bowen, Tammy Kammin, Claire Green	
17:15 - 17:30	Counselling Aspects	Sabine Hellemans	Ghent University Hospital, Ghent, Belgium
17:30 - 17:45	Patient Advocacy Toolkit for People with vEDS	Juliette Harris	Northwick Park Hospital, London, UK
17:45 - 17:55	Panel Discussion		
17:55 - 18:00	Closing Remarks		
18:00	END		