



2020

VIRTUAL EDS ECHO SUMMIT

A Virtual Scientific Conference
on EDS, HSD, and Comorbidities

AGENDA



IN ADDITION TO THE ORAL PRESENTATIONS, WE HAVE 23 ABSTRACT E-POSTERS FOR THIS EVENT. TICKET HOLDERS WILL BE EMAILED A LINK TO VIEW THE E-POSTERS. IF YOU HAVE REGISTERED BUT NOT RECEIVED THE LINK, PLEASE EMAIL: EVENTS@EHLERS-DANLOS.COM TO REQUEST IT.

DAY 1: FRIDAY OCTOBER 2, 2020

TIME (EDT)	PRESENTATION	PRESENTER
09:00 am	Welcome	Prof. Lara Bloom
9:05 am	<i>Aspirations</i> - Our First Scientific Conference Dedicated to Comorbidities in EDS and HSD	Assoc. Prof. Dr. Alan Hakim
SESSION 1 - PAIN MECHANISMS Facilitator: Assoc. Prof. Dr. Alan Hakim		
9:29 am	Introduction to Session 1	Assoc. Prof. Dr. Alan Hakim
9:34 am	Pain Mechanisms in EDS and HSD	Prof. Fransiska Malfait
10:10 am	<i>Abstract</i> - Fascial Thickness and Stiffness in Hypermobile Ehlers-Danlos Syndrome	Asst. Prof. Tina Wang
10:23 am	Live Q&A	Prof. Fransiska Malfait Asst. Prof. Tina Wang
BREAK 1 10:50 - 10:55 am		
SESSION 2 - PSYCHIATRY & PSYCHOLOGY Facilitator: Assoc. Prof. Dr. Alan Hakim		
10:55 am	Introduction to Session 2	Assoc. Prof. Dr. Alan Hakim
11:00 am	Psychiatric and Psychological Conditions in EDS and HSD	Prof. Antonio Bulbena
11:41 am	A Case of Anorexia	Dr. Yolanda Collado
11:49 pm	Live Q&A	Prof. Antonio Bulbena Dr. Yolanda Collado
BREAK 2 12:15 - 12:35 pm		
SESSION 3 - DENTAL & LARYNGEAL DISORDERS Facilitator: Assoc. Prof. Dr. Alan Hakim		
12:35 pm	Introduction to Session 3	Assoc. Prof. Dr. Alan Hakim
12:40 pm	Dental Complications in EDS	Assoc. Prof. Ines Kapferer-Seebacher
1:08 pm	Are you Choking? - Throat problems and care in EDS	Prof. Martin Birchall
1:40 pm	<i>Abstract</i> - Characterization of Laryngological Presentations and Patient Reported Outcome Measures in Patients With Ehlers-Danlos Syndromes	Dr. Chon Meng Lam
1:52 pm	Live Q&A	Assoc. Prof. Ines Kapferer-Seebacher Prof. Martin Birchall Dr. Chon Meng Lam
BREAK 3 2:10 - 2:15 pm		
SESSION 4 - RESPIRATORY DISORDERS Facilitator: Dr. Clair Francomano		
2:15 pm	Introduction to Session 4	Dr. Clair Francomano
2:20 pm	Respiratory Disorders and Their Relationship With EDS and HSD	Dr. Rebecca Bascom
2:24 pm	Respiratory Medication Burden in Persons with EDS	Dr. Radha Dhingra
2:39 pm	Respiratory Disorders and Their Relationship With EDS and HSD, <i>Continued</i>	Dr. Rebecca Bascom
3:06 pm	Live Q&A	Dr. Rebecca Bascom Dr. Radha Dhingra

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BREAK 4 3:20 - 3:25 pm		
SESSION 5 - GYNAECOLOGICAL CONCERNS & PREGNANCY Facilitator: Dr. Clair Francomano		
3:25 pm	Introduction to Session 5	Dr. Clair Francomano
3:30 pm	Gynecological Concerns and Pregnancy in EDS and HSD	Dr. Natalie Blagowidow
4:13 pm	<i>Abstract - Dyspareunia and Vulvodynia in Women With Ehlers-Danlos Syndrome: An Online Survey</i>	Jennifer Glayzer
4:28 pm	Live Q&A	Dr. Natalie Blagowidow Jennifer Glayzer
BREAK 5 4:45 - 4:50 pm		
SESSION 6 - KEYNOTE LECTURE: ORTHOPAEDIC OUTCOMES Facilitator: Dr. Clair Francomano		
4:50 pm	Introduction to Keynote	Dr. Clair Francomano
4:55 pm	<i>Keynote Lecture - Orthopaedic Outcomes in Hypermobility-Related Disorders</i>	Dr. Cathleen Raggio
5:38 pm	Close	Prof. Lara Bloom
- END -		

DAY 2: SATURDAY OCTOBER 3, 2020		
TIME (EDT)	PRESENTATION	PRESENTER
9.05 am	Welcome (Day two)	Prof. Lara Bloom
SESSION 7 - KEYNOTE LECTURE: PHYSICAL THERAPIES Facilitator: Assoc. Prof. Dr. Alan Hakim		
9:10 am	Introduction to Keynote	Assoc. Prof. Dr. Alan Hakim
9:15 am	<i>Keynote Lecture - Physical Therapies in Hypermobility-Related Disorders</i>	Dr. Jane Simmonds
BREAK 6 9:50 - 9:55 am		
SESSION 8 - NEURODIVERSITY Facilitator: Assoc. Prof. Dr. Alan Hakim		
09:55 am	Introduction to Session 8	Assoc. Prof. Dr. Alan Hakim
10:00 am	Neurodiversity: Associations and Implications in EDS and HSD	Dr. Carolina Baeza-Velasco
10:29 am	Generalized Joint Hypermobility and Dyslexia: A Case Study	Dr. Stephanie Meyer
10:38 am	Case Study - Neurodevelopmental Disorder and Hypermobility	Dr. Jessica Eccles
10:49 am	Live Q&A	Dr. Carolina Baeza-Velasco Dr. Stephanie Meyer Dr. Jessica Eccles
BREAK 7 11:15 - 11:20 am		
SESSION 9 - CARDIOVASCULAR AUTONOMIC DYSFUNCTION Facilitator: Assoc. Prof. Dr. Alan Hakim		
11:20 am	Introduction to Session 9	Assoc. Prof. Dr. Alan Hakim
11:25 am	Cardiovascular Autonomic Complications in HSD and EDS	Prof. Christopher Mathias
12:01 pm	Case Study - Tachycardia in a case of hEDS: Enough to give anyone palpitations	Assoc. Prof. Dr. Alan Hakim

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12:24 pm	Live Q&A	Prof. Christopher Mathias
BREAK 8 12:40 - 1:00 pm		
SESSION 10 - GASTROINTESTINAL DISORDERS Facilitator: Dr. Clair Francomano		
1:00 pm	Introduction to Session 10	Dr. Clair Francomano
1:05 pm	EDS, HSD, and Gastrointestinal Disorders	Prof. Qasim Aziz
1:44 pm	<i>Abstract - Hyperelastic Fibrous Tissue Disorder Is a Risk Factor for Development of Multiple Retroperitoneal and Pelvic Compression Syndromes and for Recurrences After Surgery</i>	Prof. Wilhelm Sandmann
2:00 pm	Live Q&A	Prof. Qasim Aziz Prof. Wilhelm Sandmann
SESSION 11 - THE BLADDER Facilitator: Dr. Clair Francomano		
2:25 pm	Introduction to Session 11	Dr. Clair Francomano
2:30 pm	Pelvic Floor and Bladder Disorders in EDS and HSD	Prof. Vik Khullar
3:08 pm	<i>Abstract - Parental Perceptions on Lower Urinary Tract Dysfunction of Children With Joint Hypermobility Spectrum Disorder (HSD) and Hypermobile Ehlers-Danlos Syndrome (hEDS)</i>	Marianna Veriki
3:25 pm	Live Q&A	Prof. Vik Khullar Marianna Veriki
BREAK 9 3:45–3:50 pm		
SESSION 12 - MAST CELL ACTIVATION Facilitator: Dr. Clair Francomano		
3:50 pm	Introduction to Session 12	Dr. Clair Francomano
3:55 pm	Mast Cell Activation and Immunological Concerns in EDS and HSD	Dr. Lawrence Afrin
4:32 pm	<i>Abstract - Immune dysfunction, both mast cell activation disorders and primary immune deficiency, is common among patients with hypermobile spectrum disorder (HSD) or hypermobile type Ehlers Danlos Syndrome (hEDS)</i>	Dr. Anne Maitland
4:53 pm	Live Q&A	Dr. Lawrence Afrin Dr. Anne Maitland
5:10 pm	Close	Prof. Lara Bloom
- END -		

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The Planners and Presenters of this activity disclose that they have no financial relationships with any commercial interest. Alan Hakim, MD; Stacey Simmonds, Lara Bloom, Dr. Anne Maitland, Prof. Antonio Bulbena, Dr. Carolina Baeza-Velasco, Dr. Cathleen Raggio, Dr. Chon Meng Lam, Prof. Christopher Mathias, Dr. Clair Francomano, Prof. Fransiska Malfait, Assoc. Prof. Ines Kapferer-Seebacher, Dr. Jane Simmonds, Jennifer Glayzer, Dr. Jessica Eccles, Dr. Lawrence Afrin, Marianna Veriki, Prof. Martin Birchall, Dr. Natalie Blagowidow, Prof. Qasim Aziz, Dr. Radha Dhingra, Dr. Rebecca Bascorn, Dr. Stephanie Meyer, Asst. Prof. Tina Wang, Prof. Vik Khullar, Prof. Wilhelm Sandmann, and Dr. Yolanda Collado.



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