



The
**Ehlers
Danlos**
Society

2020

VIRTUAL SUMMER CONFERENCE

A G E N D A

FRIDAY, JULY 10

TIME	SESSION	SPEAKER
10.00 am (EDT US/Canada)	Welcome & Update	Susan Hawkins & Lara Bloom
10:30 am	Diagnosing Rarer Types Introduction	Dr. Clair Francomano
10:35 am	Genetics for Beginners	Dr. Christina Laukaitis
11:05 am	How to Make Sense of My Genetic Test Mutations and Variants of Unknown Significance Explained	Prof. Fransiska Malfait
11:35 am	Q&A	Drs. Francomano, Laukaitis, Malfait
11:50 am	BREAK & Community Voices	
12.00 noon	Vascular Complications in EDS Introduction	Dr. Sherene Shalhub
12:05 pm	Types of Complications and Their Investigations	To be confirmed
12:35 pm	Navigating an Emergency Room	Dr. James Black
1:05 pm	Q&A	Drs. Shalhub, Black
1:20 pm	BREAK & Community Voices	
1:50 pm	Living With a Rare Disease (Part 1) Introduction	Prof. Fransiska Malfait
1:55 pm	The Challenges of Living With a Rare Disorder	Prof. Fransiska Malfait
2:25 pm	Supporting Families of Children With a Rare Disease	Dr. Lauren Puryear
2:55 pm	BREAK & Information on vEDS ECHO	
3:05 pm	Living With a Rare Disease (Part 2) Introduction	Prof. Fransiska Malfait
3:10 pm	Managing GI Complications	Prof. Qasim Aziz
3:40 pm	Managing Skin Complications	Dr. Nigel Burrows
4:10 pm	BREAK & Information on Support Groups	
4:20 pm	Ask the Specialists Open Q&A with Drs. Aziz, Burrows, Francomano, Malfait, Puryear, Shalhub	Lara Bloom
4:50 pm	Final Thoughts	

SATURDAY, JULY 11

TIME	SESSION	SPEAKER
10.00 am (EDT US/Canada)	Introduction	Susan Hawkins & Lara Bloom
10:05 am	HSD & hEDS Introduction	Dr. Alan Hakim
10:10 am	What Is HSD	To be confirmed
10:35 am	What Is hEDS	Dr. Alan Hakim
11:00 am	Q&A	Dr. Alan Hakim
11:20 am	BREAK & Community Voices	
11:30 am	ENT & Dental Introduction	Dr. Alan Hakim
11:35 am	ENT Complications and Management	Dr. Martin Birchall
11:55 am	ENT Symptoms & Treatment for EDS & Hypermobility Disorders: A Speech & Language Therapist Perspective	Mr Gary Wood
12:15 pm	Dental Complications in EDS	Dr. Ines Kapferer-Seebacher
12:35 pm	Q&A	Drs. Hakim, Birchall, Kapferer-Seebacher
12:50 pm	BREAK & Community Voices	
1:20 pm	Gynecology & Bladder Introduction	Dr. Clair Francomano
1:25 pm	Women's Health Concerns	Dr. Natalie Blagowidow
1:50 pm	Disorders of Bladder Function	Prof. Vik Khullar
2:15 pm	Pregnancy	To be confirmed
2:40 pm	Q&A	Drs. Francomano, Blagowidow, Khullar
3:00 pm	BREAK & Community Voices	
3:10 pm	Mast Cells & Respiratory Introduction	Dr. Clair Francomano
3:15 pm	Treatment of Allergy & Immunology Issues	Dr. Anne Maitland
3:40 pm	Breathing Difficulties in EDS	To be confirmed
4:05 pm	Q&A	Drs. Francomano, Maitland, Bascom
4:20 pm	BREAK & Information on ECHO Professionals	
4:30 pm	Special session to be confirmed	
5:00 pm	Final Thoughts	

SUNDAY, JULY 12

TIME	SESSION	SPEAKER
10.00 am (EDT US/Canada)	Introduction	
10:05 am	Self-Management and Effective Doctor Appointments	Shani Weber
10:35 am	EDS ECHO - Advocacy	Lara Bloom
10:45 am	Reflections From an EDS ECHO Advocate	Owen Moore
11:00 am	Neurodiversity Introduction	Dr. Hakim
11:05 am	Autism, EDS, and HSD	Dr. Carolina Baeza-Velasco
11:30 am	Supporting People With ADHD	Dr. James Kustow
11:55 am	Q&A	Drs. Hakim, Baeza-Velasco, Kustow
12:10 pm	BREAK & Community Voices	
12:20 pm	Musculoskeletal Concerns Introduction	Dr. Jane Simmonds
12:25 pm	Principles of Physical Therapy	Dr. Leslie Russek
12:50 pm	Pros and Cons of Joint Surgery	Dr. Cathy Raggio
1:15 pm	Q&A	Drs. Simmonds, Russek, Raggio
1:30 pm	BREAK & Community Voices	
1:50 pm	GI & Nutrition Introduction	Dr. Clair Francomano
1:55 pm	Investigation and Medicinal Treatment of GI Concerns	Prof. Qasim Aziz
2:15 pm	Nutritional Approaches to Treating GI Concerns	Dr. Heidi Collins
2:35 pm	Q&A	Drs. Francomano, Aziz, Collins
2:50 pm	BREAK & Information on Webinars & Helpline	
3:00 pm	Autonomics & Anxiety Introduction	Dr. Alan Hakim
3:05 pm	Fast Heart Rate, Low Blood Pressure	Dr. Peter Rowe
3:25 pm	Anxiety and Hypermobility	Dr. Jessica Eccles
3:45 pm	Q&A	Drs. Hakim, Rowe, Eccles
4:00 pm	BREAK & Information on Future Events	
4:10 pm	Ask the Specialists with Aziz, Hakim, Malfait, Simmonds, Weber	Lara Bloom
4:40 pm	Virtual Awards	
5:00 pm	Closing Remarks	
5:15 pm	Conference End	