



The  
**Ehlers  
Danlos**  
Society

2020

**VIRTUAL  
SUMMER  
CONFERENCE**  
AGENDA

**DAY 1: FRIDAY JULY 10, 2020**

<b>TIME</b>	<b>SESSION</b>	<b>SPEAKER</b>
10.00 am (EDT US/Canada)	Welcome & Update	Susan Hawkins & Lara Bloom
<b>SESSION 1</b>		
10:20 am	Diagnosing Rarer Types Introduction	Dr. Clair Francomano
10:22 am	Genetics for Beginners	Dr. Christina Laukaitis
10:49 am	How to Make Sense of My Genetic Test Mutations and Variants of Unknown Significance Explained	Prof. Fransiska Malfait
<b>SESSION 2</b>		
11:06 am	Q&A	Drs. Francomano, Laukaitis, Malfait
11:36 am	BREAK & Community Voices	
<b>SESSION 3</b>		
11:50 am	Vascular Complications in EDS Introduction	Dr. Sherene Shalhub
11:52 am	Types of Complications and Their Investigations	Dr. Sherene Shalhub
12:19 pm	Navigating an Emergency Room	Dr. James Black
<b>SESSION 4</b>		
12:37 pm	Q&A	Drs. Shalhub, Black
1:05 pm	BREAK & Community Voices	
<b>SESSION 5</b>		
1:33 pm	Living with a Rare Disease (Part 1) Introduction	Prof. Fransiska Malfait
1:35 pm	The Challenges of Living With a Rare Disorder	Prof. Fransiska Malfait
2:00 pm	Supporting Families of Children With a Rare Disease	Dr. Lauren Puryear
2:26 pm	BREAK & Information on vEDS ECHO	
<b>SESSION 6</b>		
2:49 pm	Living with a Rare Disease (Part 2) Introduction	Prof. Fransiska Malfait
2:52 pm	Managing GI Complications	Prof. Qasim Aziz
3:28 pm	Managing Skin Complications	Dr. Nigel Burrows
4:00 pm	BREAK & Information on Support Groups	
<b>SESSION 7</b>		
4:20 pm	Ask the Specialists Open Q&A with Drs. Aziz, Burrows, Francomano, Malfait, Puryear, Shalhub	Lara Bloom
4:59 pm	Final thoughts	

**DAY 2: SATURDAY JULY 11, 2020**

<b>TIME</b>	<b>SESSION</b>	<b>SPEAKER</b>
10.00 am (EDT US/Canada)	Introduction	Susan Hawkins & Lara Bloom
<b>SESSION 8</b>		
10:04 am	HSD & hED - Introduction	Dr. Alan Hakim
10:06 am	What is HSD	Dr Howard Levy
10:37 am	What is hEDS	Dr. Alan Hakim
<b>SESSION 9</b>		
11:12 am	Q&A	Dr. Alan Hakim
11:25 am	BREAK & Community Voices	
<b>SESSION 10</b>		
11:30 am	ENT & Dental - Introduction	Dr. Alan Hakim
11:31 am	ENT Complications and Management	Dr. Martin Birchall
11:59 am	ENT Symptoms & Treatment for EDS & Hypermobility Disorders: A Speech & Language Therapist Perspective	Mr Gary Wood
12:37 pm	Dental Complications in EDS	Dr. Ines Kapferer-Seebacher
<b>SESSION 11</b>		
12:55 pm	Q&A	Drs. Hakim, Birchall, Kapferer-Seebacher
1:10 pm	BREAK & Community Voices	
<b>SESSION 12</b>		
1:20 pm	Gynecology & Bladder - Introduction	Dr. Clair Francomano
1:22 pm	Women's Health Concerns	Dr. Natalie Blagowidow
1:48 pm	Disorders of Bladder Function	Prof. Vik Khullar
2:05 pm	Pregnancy	Dr Melissa Russo
<b>SESSION 13</b>		
2:37 pm	Q&A	Drs. Francomano, Blagowidow, Khullar
3:00 pm	BREAK & Community Voices	
<b>SESSION 14</b>		
3:10 pm	Mast Cells & Respiratory - Introduction	Dr. Clair Francomano
3:12 pm	Treatment of Allergy & Immunology Issues	Dr. Anne Maitland
3:42 pm	Breathing Difficulties in EDS	Dr Rebecca Bascom
<b>SESSION 15</b>		
4:08 pm	Q&A	Drs. Francomano, Maitland, Bascom
4:23 pm	BREAK & Information on ECHO Professionals	
<b>SESSION 16</b>		
4:30 pm	Q&A with Miss America	
5:05 pm	Final thoughts	

**DAY 3: SUNDAY JULY 12, 2020**

<b>TIME</b>	<b>SESSION</b>	<b>SPEAKER</b>
10.00 am (EDT US/Canada)	Introduction	Lara Bloom & Susan Hawkins
<b>SESSION 17</b>		
10:04am	Self Management and Advocacy - Introduction	Dr. Alan Hakim
10:06 am	Self-Management and Effective Doctor Appointments	Shani Weber
10:36 am	EDS ECHO - Advocacy	Lara Bloom
10:43 am	Reflections From an EDS ECHO Advocate	Owen Moore
<b>SESSION 18</b>		
10:58 am	Neurodiversity - Introduction	Dr. Hakim
11:00 am	Autism, EDS, and HSD	Dr. Carolina Baeza-Velasco
11:20 am	Supporting People with ADHD	Dr. James Kustow
<b>SESSION 19</b>		
11:48 am	Q&A	Drs. Hakim, Baeza-Velasco, Kustow
12:10 pm	BREAK & Community Voices	
<b>SESSION 20</b>		
12:25 pm	Musculoskeletal Concerns - Introduction	Dr. Jane Simmonds
12:30 pm	Principles of Physical Therapy	Dr. Leslie Russek
12:55 pm	Pros and Cons of Joint Surgery	Dr. Cathy Raggio
<b>SESSION 21</b>		
1:15 pm	Q&A	Drs. Simmonds, Russek, Raggio
1:30 pm	BREAK & Community Voices	
<b>SESSION 22</b>		
1:49 pm	GI & Nutrition - Introduction	Dr. Clair Francomano
1:51 pm	Investigation and Medicinal Treatment of GI Concerns	Prof. Qasim Aziz
2:14 pm	Nutritional Approaches to Treating GI Concerns	Dr. Heidi Collins
<b>SESSION 23</b>		
2:54 pm	Q&A	Drs. Francomano, Aziz, Collins
<b>SESSION 24</b>		
3:09 pm	Autonomics & Anxiety - Introduction	Dr. Alan Hakim
3:10 pm	Fast Heart Rate, Low Blood Pressure	Dr. Peter Rowe
3:25 pm	Anxiety and Hypermobility	Dr. Jessica Eccles
<b>SESSION 25</b>		
3:45 pm	Q&A	Drs. Hakim, Rowe, Eccles
4:00 pm	BREAK & Information on Future Events	
<b>SESSION 26</b>		
4:10 pm	Ask the Specialists with Aziz, Hakim, Malfait, Simmonds, Weber	Lara Bloom
<b>SESSION 27</b>		
4:50 pm	Virtual awards	Lara Bloom
5:15 pm	Final thoughts	