



The
**Ehlers
Danlos**
Society

VIRTUAL SUMMER CONFERENCE

MANAGING DAILY LIFE WITH EDS & HSD

AGENDA

JUNE 26-27, 2021



AGENDA

DAY 1: JUNE 26, 2021

TIME (EDT)	SESSION/PRESENTATION	SPEAKER(S)
08:20 - 08:50	Pre-event: Relax your stripes - Head, neck and shoulder release through a guided breath meditation.	Jeannie Di Bon
09:00 - 09:12	Welcome to Day 1	Prof. Lara Bloom Susan Hawkins
SESSION 1: COMPLEMENTARY THERAPIES		
09:12 - 09:15	Introduction to Sessions 1 & 2	Dr. Alan Hakim
09:15 - 09:45	Presentation: Integrative Approaches to the Management of EDS & HSD - CME CREDITS AVAILABLE	Dr. Tina Wang
09:45 - 10:10	Presentation: Medical Cannabis - CME CREDITS AVAILABLE	Dr. Jordan Tishler
10:10 - 10:32	Presentation: Prolotherapy - CME CREDITS AVAILABLE	Dr. Fraser Burling
10:32 - 11:00	Q&A: Dr. Tina Wang, Dr. Jordan Tishler, Dr. Fraser Burling and Dr. Alan Hakim	
11:00 - 11:20	BREAK	
SESSION 2: PHYSICAL THERAPY		
11:20 - 11:50	Presentation: Breathing, Sleeping, and Posture - CME CREDITS AVAILABLE	Dr. Leslie Russek
11:50 - 12:15	Interactive Presentation: Time for change - taking control of your symptoms - CME CREDITS AVAILABLE	Dr. Jane Simmonds
12:15 - 12:42	Presentation: Pilates and Movement Therapy - CME CREDITS AVAILABLE	Jeannie Di Bon
12:42 - 13:05	Q&A: Dr. Leslie Russek, Dr. Jane Simmonds and Jeannie Di Bon	
13:05 - 13:35	LONG BREAK - Sponsored by Body Braid	
SESSION 3: ADVOCACY		
13:35 - 13:40	Introduction to Sessions 3 & 4	Shani Weber
13:40 - 14:00	Presentation: Empowering Young Adults with Chronic and Rare Conditions	Sneha Dave Rosa Kelekian
14:00 - 14:30	Presentation: Self-advocacy and advocating for others	Jessica Temple
14:30 - 14:45	Presentation: The Journey of an EDS ECHO Advocate	Owen Moore
14:45 - 14:51	Presentation: Community voices	Laura Romano (cIEDS)
14:51 - 15:20	Q&A: Sneha Dave & Rosa Kelekian, Jessica Temple and Owen Moore	
15:20 - 15:40	BREAK	
SESSION 4: NAVIGATING EDUCATION & WORK		
15:40 - 16:17	Presentation: Navigating Education and Work with a Chronic Condition	Emily Rich
16:17 - 16:42	Interactive Presentation: Finding a new norm - Work	Shani Weber
16:42 - 17:08	Interactive Presentation: Making it through higher education	Marisa Bergfield
17:08 - 17:35	Q&A: Emily Rich, Shani Weber and Marisa Bergfield	
17:35 - 17:40	CLOSE: Prof. Lara Bloom	

CME APPROVED PRESENTATION
 Q&A
 SESSION
 BREAK
 INTERACTIVE PRESENTATION

PLEASE NOTE: SINCE THIS IS A LIVE EVENT, TIMES ARE APPROXIMATE AND ARE SUBJECT TO CHANGE. IF YOU MISS ANYTHING LIVE, YOU CAN CATCH UP BY WATCHING THE RECORDINGS BACK.

AGENDA

DAY 2: JUNE 27, 2021

TIME (EDT)	SESSION/PRESENTATION	SPEAKER(S)
08:20 - 08:44	Pre-event: Relax your stripes - Soften the belly & unwind pelvic tension with gentle mindful movements and breath.	Jeannie Di Bon
08:44 - 09:01	Welcome to Day 2	Prof. Lara Bloom Susan Hawkins
SESSION 5: THE MIND-BODY CONNECTION		
09:01 - 09:04	Introduction to Sessions 5 & 6	Dr. Alan Hakim
09:04 - 09:28	Presentation: Pacing, Goal Setting, & Motivation - CME CREDITS AVAILABLE	Dr. Penelope Cream
09:28 - 09:53	Discussion: Anxiety and Hypermobility - CME CREDITS AVAILABLE	Dr. Stephen Porges
09:53 - 10:17	Interactive Presentation: Managing ADHD - CME CREDITS AVAILABLE	Dr. James Kustow
10:17 - 10:45	Q&A: Dr. Alan Hakim, Dr. Penelope Cream, Dr. Stephen Porges and Dr. James Kustow	
10:45 - 11:00	BREAK	
SESSION 6: PAIN & FATIGUE		
11:00 - 11:28	Presentation: Self-Management: Living with Ehlers-Danlos Syndrome - CME CREDITS AVAILABLE	Stephanie Carroll
11:28 - 11:53	Presentation: Pain Management - CME CREDITS AVAILABLE	Dr. Pradeep Chopra
11:53 - 12:16	Presentation: Fatigue Management - CME CREDITS AVAILABLE	Dr. Alan Pocinki
12:16 - 12:40	Q&A: Stephanie Carroll, Dr. Pradeep Chopra and Dr. Alan Pocinki	
12:40 - 13:10	LONG BREAK - Sponsored by Body Braid	
SESSION 7: CHILDREN & YOUNG PEOPLE WITH EDS & HSD		
13:10 - 13:19	Introduction to Sessions 7 & 8	Shani Weber
13:19 - 13:52	Presentation: Supporting children and young people with EDS & HSD	Sarah Schwartz
13:52 - 14:17	Interactive Presentation: Caring for the Caregivers: Sensory Self-Care in Microments Per Day	Cristol O'Loughlin
14:17 - 14:42	Interactive Presentation: Keeping active	Dr. Jane Simmonds
14:42 - 14:49	Presentation: Community voices	Katya Kozary (hEDS)
14:49 - 15:10	Q&A: Sarah Schwartz, Cristol O'Loughlin, Dr. Jane Simmonds and Katya Kozary	
15:10 - 15:20	BREAK	
SESSION 8: THINGS TO HELP IN DAILY LIFE		
15:20 - 15:50	Presentation: Things to help in Daily Life	Maggie Buckley
15:50 - 16:15	Panel Workshop: Living with a rare disease as a young adult	Seth Rotberg, Emily Hall and Marcelle Longlade
16:15 - 16:40	Interactive Presentation: Working with your Health Professional Team	Shani Weber
16:40 - 17:05	Presentation: Nutrition & Hydration	Lorna Ryan
17:05 - 17:25	Q&A: Maggie Buckley, Seth Rotberg, Emily Hall, Marcelle Longlade, Shani Weber and Lorna Ryan	
17:25 - 17:30	COMFORT BREAK	

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DAY 2: JUNE 27, 2021

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SESSION 9: AWARDS CEREMONY		
17:30 - 17:31	Introduction to awards ceremony	Cami Clune
17:31 - 17:55	Awards Ceremony honoring outstanding Community Members & Healthcare Professionals	Prof. Lara Bloom
17:55 - 18:00	Closing Performance	Cami Clune
18:00 - 18:05	Farewell	Prof. Lara Bloom

 CME APPROVED PRESENTATION  Q&A  SESSION  BREAK  INTERACTIVE PRESENTATION

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