

EDS GLOBAL LEARNING CONFERENCE 2022

Thursday, August 4, 2022

Time	Session	Chair	Speaker
8.45 - 9.00	Welcome to the event		Susan Hawkins & Prof. Lara Bloom
SESSION 1	PREGNANCY & CHILDBIRTH	Dr Natalie Blagowidow	
9:00 - 9:20	Tools & strategies for Pregnancy, Childbirth and Post-partum in EDS & HSD		Jacqui Main
9:20 - 9:40	High-Risk Pregnancy and Delivery Methods for Women with Ehlers-Danlos Syndromes		Dr. Melissa Russo
9:40 - 10:10	Pregnancy and Early Motherhood in hEDS and HSD		Dr. Sally Pezaro
10:10 - 10:30	Panel Q&A		
10:30 - 11:00	BREAK		
SESSION 2A	THE PRE-PUBESCENT YEARS	Dr. Ellen Elias	
11:00 - 11:20	Assessment and Management of the Child		Dr. Jane Simmonds
11:20 - 11:40	When to Get A Child Tested for EDS		Dr. Sarah Schwartz

11:40 - 12:00	hEDS in Pediatric Patients		Dr. Ellen Elias
SESSION 2B	KEEPING CHILDREN ACTIVE	Dr. Leslie Russek	
12:00 - 12:20	Keeping Children Active: Physical Therapy		Patricia Stott
12:20 - 12:40	Keeping Children with EDS and HSD Active: A Podiatrist's Perspective		Sophie Roberts
12:40 - 1:00	Panel Q&A		
1:00 - 2:00	LUNCH		
SESSION 3	THINGS TO ASSIST CHILDREN IN DAILY LIFE	Dr. Heidi Collins	
2:00 - 2:20	School Adaptations and Occupational Therapy		Dr. Jess Salyers
2:20 - 2:40	'Regulate' – a parent's guide to emotional dysregulation		Dr. James Kustow
2:40 - 3:00	Holistic Approaches to Care for Children and Adolescents with Hypermobility and EDS		Constance O'Connor
3:00 - 3:20	Panel Q&A		
3:20 - 3:50	BREAK		
SESSION 4	CASE STUDIES ON CHILDREN WITH EDS & HSD	Dr. Ellen Elias	
3:50 - 4:05	Fabricated or Induced Illness (FII): An Exploration of Issues		Emma-Louise Williams

	Within the United Kingdom		
4:05 - 4:20	Case Study on a Child with EDS: Physical Therapy		Patricia Stott
4:20 - 4:35	Case Studies on Children with EDS: Podiatry		Sophie Roberts
4:35 - 5:00	Panel Q&A		
5:00	END		Prof. Lara Bloom

Friday, August 5, 2022

Time	Session	Chair	Speaker
7.30 - 8.15	Morning stretch and relaxation		Jeannie Di Bon
8.45 - 9.00	Welcome		Prof. Lara Bloom
SESSION 5A	PSYCHOLOGY	Dr. James Kustow	
9.00 - 09.25	Coping with a Diagnosis		Dr. Paldeep Atwal
9.25 - 09.50	Brain-hacking the psychological pathways that maintain anxiety and depression		Dr. Chad Shepherd
9.50 - 10.15	'Regulate' – the physiology of dysregulated emotions...and how to tame them		Dr. James Kustow
SESSION 5B	ORTHOPEDIC MANAGEMENT	Dr. James Kustow	
10.15 - 10.35	The Role of Upper Extremity Surgery in Patients with Joint Hypermobility/EDS		Dr. William Ericson

10.35 - 10.55	Foot and Ankle Update		Dr. Patrick Agnew
10:55 - 11.30	Panel Q&A		
11.30 - 12:00	BREAK		
SESSION 6A	THE CHALLENGES OF LIVING WITH A RARE DISORDER	Emily Rich	
12:00 - 12:20	The Challenges of Living with a Rare Type of EDS		Dr. Serwet Demirdas
12:20 - 12:40	Supporting Families of a Child with a Rare Disease		Maureen Galindo
12.40 - 1:00	Looking Ahead: The potential for gene therapies		Dr. Christina Laukaitis
SESSION 6B	YOUNG ADULTHOOD	Emily Rich	
1:00 - 1:20	Navigating the Workplace		Emily Block
1.20 - 1:35	Building Your EDS & HSD Toolkit		Scarlett Eagle
1.35 - 2:00	Panel Q&A		
2:00 - 3:00	LUNCH		
SESSION 7A	BRUISING, BLEEDING, & SKIN	Dr. Christina Laukaitis	

3:00 - 3:20	Bruised, Bleeding, and Broken: Cutaneous presentations in EDS		Dr. Mark Lavallee
3:20 - 3:40	HSD, EDS and Bleeding Disorders: Coincidence or Comorbid?		Dr. Rebecca Schaffer, DDS
SESSION 7B	PAIN MEDICATION & ALTERNATIVE TREATMENTS	Dr. Isabelle Brock	
3:40 - 4:05	The Muldowney Protocol: How it Works and Roadblocks to Progress.		Kevin & Kathleen Muldowney
4:05 - 4:25	Drug Intolerance in hypermobile EDS and Pharmacogenomics as a Tool for Personalized Drug Management		Dr. Adrijana Kekic
4:25 - 4:45	A Quick Intro to Medical Cannabis For EDS & HSD Folk		Dr. Jordan Tishler
4:45 - 5:00	Mindfulness - impact and effectiveness for hypermobility		Jeannie Di Bon
5:00 - 5:30	Panel Q&A		
5:30 - 6:00	BREAK		
SESSION 8	SEX & INTIMACY	Dr. Natalie Blagowidow	
6:00 - 6:20	Breaking the Stigma around Sex and Intimacy		Natasha Silverman
6:20 - 6:40	Why Does Sex Hurt? Vulvar Pain & Pain During Sex in Females		Jennifer Glayzer
6:40-7:00	Pelvic Pain, Bleeding, & Incontinence in EDS & HSD		Dr. Sumana Koduri
7:00-7:20	Panel Q&A		
7:20	END		Prof. Lara Bloom

Saturday, August 6, 2022

Time	Session	Session Chair	Speaker
8.45 - 9.00	Welcome		Prof Lara Bloom
SESSION 9A	HEAD AND NECK CONCERNS	Dr. Dacre Knight	
9.00 - 9.20	Head and Neck Issues		Dr. David Saperstein
9.20 - 9.40	Facial pain and TMJ disorders		Dr. Shar Hashemi
9.40 - 10.00	Are you Choking? Throat problems and care in EDS		Dr. Martin Birchall
SESSION 9B	AUTONOMIC DYSFUNCTION	Dr. Gisela Chelimsky	
10.00 - 10.20	Tips & Tricks for Managing Autonomic Concerns		Emily Rich
10.20 - 10.40	The Role and Treatment of Autonomic Dysfunction in EDS-Associated Sleep Disorders		Dr. Alan Pocinki
10.40 - 11.00	Managing Gastrointestinal Autonomic Complications		Dr. Gisela Chelimsky
11.00 - 11.30	Panel Q&A		
11.30 - 12:00	BREAK		
SESSION 10A	GASTROINTESTINAL & UROGYNECOLOGICAL CONCERNS	Dr. Natalie Blagowidow	

12.00 - 12.20	Gastrointestinal Concerns in HSD and EDS		Dr. Laura Pace
12.20 - 12.40	Diet, Supplements, and Nutrition		Dr. Heidi Collins
12.40 - 1.00	Hypermobility and the Pelvic Floor		Dr. John Heusinkveld
1.00 - 1.20	MCAD Manifestations of GU and GI disease		Dr. Anne Maitland
1.20 - 1.40	Panel Q&A		
1:40 - 2:40	LUNCH		
SESSION 10B	AGING	Dr. Clair Francomano	
2:40 - 3.00	Managing Deconditioning		Dr. Leslie Russek
3:00 - 3.20	Clinical decision making in shoulder hypermobility – the who, what, when, where and why		Dr. Nimish Mittal
3:20 - 3.40	Living and Aging with Hypermobility Syndromes		Dr. Irman Forghani
3:40 - 4.00	Blood and Organ Donation in Ehlers-Danlos Syndrome		Dr Clair Francomano
4.00 - 4.20	Panel Q&A		
4:20 - 4:50	BREAK		
SESSION 11	LOOKING AHEAD - RESEARCH TO GET EXCITED ABOUT		
		Dr. Christina Laukaitis	

4:50 - 5:05	New Insight into Genetics of hEDS and Hope for the Future		Dr. Chip Norris, Dr. Christina Laukaitis, Dr. Clair Francomano
5:05 - 5:20	Research in Classical Ehlers Danlos Syndrome - Unfolding Key Molecular Mechanisms On Our Way to Disease Specific Treatments		Dr. Keren Machol
5:20 - 5:35	Rationale and updates for a trial of enzastaurin in vEDS		Dr. Hal Dietz
5:35 - 5:50	Research plans for the EDS Society		Dr. Clair Francomano
5:50 - 6:05	Gaps in research (title TBD)		Dr. Fraser Henderson
6:05 - 6:10	CLOSE		Prof Lara Bloom