



EDS ECHO SUMMIT SERIES

VASCULAR EHLERS-DANLOS SYNDROMES

A Comprehensive Conference
on Care for Individuals with vEDS

AGENDA

JULY 30-31, 2021

AGENDA

JULY 30

TIME <small>(Eastern US & Canada)</small>	PRESENTATION TITLE	PRESENTER(S)
10:40 - 10:50	Webinar opens for attendees to join	
	Welcome to the event	Prof. Lara Bloom
	Intro and objective of the event	Dr. Sherene Shalhub
SESSION 1 - BIOLOGY AND GENETICS - CHAIR: DR. PETER BYERS		
	Welcome to Session 1	
	Genetics and Molecular Biology in vEDS	Lauren Puryear
	Interpreting the genetic testing report	Duncan Baker & Neeti Ghali
	How do we interpret data from mice models?	Dr. Peter Byers
	Community Voices	
	BREAK	
SESSION 2 - MANAGING DAILY LIFE WITH VEDS - CHAIR: DR. GLENDA SOBEY		
	Welcome to Session 2	Dr. Glenda Sobey
	Outpatient medical management in vEDS	Dr. Fleur Van Dijk & Dr. Glenda Sobey
	Psychosocial issues in patients living with vEDS	Lianne Barrett
	Exercise with vEDS	Dr. Siddarth Prakash
	What my toolbox looks like, and how you could build yours	Katie Wright
	Community Voices	
	Live Q&A & Panel Discussion	
	BREAK	
SESSION 3 - OTHER MANIFESTATIONS OF VEDS - CHAIR: DR. XAVIER JEUNEMAITRE		
	Welcome to Session 3	Dr. Xavier Jeunemaitre
	Pulmonary abnormalities in vEDS	Dr. Enid Neptune
	Intestinal emergencies in vEDS	Dr. Jessica A. Zagory
	Gastrointestinal abnormalities in vEDS	Dr. Laura Pace
	BREAK	
	BP control and management of autonomic dysfunction	Dr. Satish Raj
	Migraines	Dr. Manjit Matharu
	Musculoskeletal abnormalities in vEDS	Dr. Alan Hakim
	Community Voices	
	Live Q&A & Panel Discussion	
17:15 - 17:20	Close & Goodbye	

SESSION
 COMMUNITY VOICES
 BREAK
 Q&A

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

AGENDA

JULY 31

TIME (Eastern US & Canada)	PRESENTATION TITLE	PRESENTER(S)
10:45 - 10:55	Webinar opens for attendees to join	
	Welcome to the event	
SESSION 4 - FAMILY PLANNING & PREGNANCY		
	Welcome to Session 4 - Session chair: Diana Johnson	
	Family planning, anticipating & managing pregnancy complications	Dr. Melissa Russo
	Children with vEDS	Dr. Shaine Morris
	School Adaptations for vEDS	Jared Griffin
	Community Panel: Conversation of Family Life with vEDS	
	Live Q&A & Panel Discussion	
	BREAK	
SESSION 5 - VASCULAR ABNORMALITIES IN VEDS: PART 1 - SESSION CHAIR: DR. SHERENE SHALHUB		
	Welcome to Session 5 & 6 - Session chair: Dr. Sherene Shalhub	
	Hematologic abnormalities in vEDS	Dr. Rohith Jesudas
	Venous disease in VEDS	Dr. Sheila Coogan
	Carotid, vertebral, and subclavian arteries in VEDS	Dr. John Ohman
	Community Voices	
	Live Q&A & Panel Discussion	
	BREAK	
SESSION 6 - VASCULAR ABNORMALITIES IN VEDS: PART 2 - SESSION CHAIR: DR. SHERENE SHALHUB		
	Visceral arteries in VEDS	Dr. Amani Politano
	The aorta and iliac arteries in VEDS	Dr. Sherene Shalhub
	Community Voices	
	Live Q&A & Panel Discussion	
	BREAK	
SESSION 7 - LATEST RESEARCH IN VEDS ROUNDTABLE		
	Introduction to Session 7 - Session chair: Dr. Xavier Jeunemaitre	
	Meds 4 vEDS Clinical Trial	Dr. Sherene Shalhub
	Pediatric Manifestations	Dr. Shaine Morris
	vEDS Health-related quality of life study	Dr. Daphne Fulton
	Ambulatory BP study	Dr. Siddharth Prakash

SESSION
 COMMUNITY VOICES
 BREAK
 Q&A

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JULY 31

TIME (Eastern US & Canada)	PRESENTATION TITLE	PRESENTER(S)
	BREAK	
	Natural History Study Update	Dr. Stephanie Wallace
	Dutch Cohort	Dr. Jessica Bos
	Rationale for a trial of PKC inhibition in vascular Ehlers-Danlos syndrome	Dr. Hal Dietz
	Gene Modifiers Loci Associated to Colonic Perforation	Dr. Xavier Jeunamaitre
	Live Q&A & Panel Discussion	
18:10 - 18:15	Close & Goodbye	

 SESSION  COMMUNITY VOICES  BREAK  Q&A

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