



# Ehlers-Danlos Syndromes and Associated Conditions:

## Awareness and Education Seminar

**September 7, 2019**  
**8:15AM-5:00PM**

**University of  
Missouri-Kansas City  
Volker Campus: Pierson  
Auditorium  
5000 Holmes Street  
Kansas City, Missouri 64110**



*If you hear hoof beats...*

*Think zebra.*



### **Topics To Be Covered:**

Genetics, Cardiology, Gastroenterology,  
Dysautonomia, Mast Cell Activation Syndrome,  
Physical Therapy, Occult Tethered Cord, Chronic  
Pain Management and Connecting the Dots  
between Medical Complexities

### **Provided By:**

EDSKC Collaboration Inc. in partnership with  
clinicians from Children's Mercy Kansas City and  
the University of Kansas Medical Center

# Agenda

7:30 AM	Check-In
8:15 AM	Welcome and Opening Remarks, <i>Wendy Cogan, BSN, Program Chair</i>
8:30 AM	Recent Advances in Diagnosis of Ehlers-Danlos Syndromes, <i>Eric Rush, MD, FAAP, FACMG</i>
9:00 AM	An Overview of Medical Complexities Associated with Ehlers-Danlos Syndromes – An Approach to Diagnosis and Management, <i>Ellen Roy Elias, MD</i>
10:00 AM	Break
10:15 AM	EDS and Your Heart. What You Need to Know, <i>Lindsey Malloy-Walton, DO, MPH</i>
11:00 AM	The Growing Roles of EDS and Orthostatic Intolerance in Pediatric Gastroenterology, <i>John E. Fortunato, MD</i>
11:50 AM	Box Lunch Provided
12:20 PM	Ehlers-Danlos Syndromes and Fellow Traveler Mast Cell Activation Syndrome, <i>Anne Maitland, MD, PhD</i>
1:10 PM	Physical Therapy Specialized for the Patient with Hypermobility Disorders, <i>Noelle Dowma, DPT, BFA, PMA-CPT</i>
1:40 PM	Chronic Pain in Children and Adolescents with Ehlers-Danlos Syndromes, <i>William Black, PhD, HSP</i>
2:10 PM	Break
2:25 PM	Managing the Occult Tethered Cord Syndrome in EDS, <i>Petra Klinge, MD, PhD, MA, IFAANS</i>
3:15 PM	Ehlers-Danlos Syndromes - Connecting the Dots, <i>Pradeep Chopra, MD, MHCM</i>
4:15 PM	Q&A Clinician Panel, moderated by <i>Jordan Jones, DO, MS</i>
5:00 PM	Adjourn
5:00 PM	Concurrent Support Sessions (post seminar): <ul style="list-style-type: none"><li>- Teen/Young Adult Patients</li><li>- Adult Patients</li><li>- Spouses, Family, Friends and Caregivers</li></ul>

# Faculty

## William Black, PhD, HSP

Assistant Professor  
University of Kansas Medical Center  
Department of Pediatrics, Division of Behavioral Pediatrics

## Pradeep Chopra, MD, MHCM

Director, Pain Management Center  
Assistant Professor (Clinical)  
Brown Medical School

## Noelle Dowma, DPT, BFA, PMA-CPT

Owner, Kinesphere Physical Therapy and Pilates

## Katie Cornwell, MBA, BFA, PMA-CPT

Owner, Kinesphere Pilates

## Ellen Roy Elias, MD

Clinical Geneticist, Director, Special Care Clinic  
Children's Hospital Colorado  
Professor, Pediatrics and Genetics  
University of Colorado School of Medicine

## John E. Fortunato, MD

Director, Neurointestinal & Motility Program  
Ann & Robert H. Lurie Children's Hospital of Chicago  
Pediatric Gastroenterology, Hepatology, and Nutrition  
Professor, Pediatrics  
Northwestern University Feinberg School of Medicine

## Jordan Jones, DO, MS

Rheumatology Division  
Children's Mercy Kansas City  
Assistant Professor of Pediatrics  
University of Missouri-Kansas City School of Medicine

## Petra Klinge, MD, PhD, MA, IFAANS

Director, Pediatric Neurosurgery and Division Director, Center for CSF Disorders of the Brain and Spine  
Brown University and Hasbro Children's Hospital  
Professor of Neurosurgery  
Warren Alpert Medical School of Brown University

## Anne Maitland, MD, PhD

Department of Medicine, Division of Allergy & Clinical Immunology  
Mount Sinai Hospital  
Assistant Professor  
Icahn School of Medicine at Mount Sinai

## Lindsey Malloy-Walton, DO, MPH

Pediatric Electrophysiologist, Pediatric Cardiology  
Children's Mercy Kansas City  
Assistant Professor of Pediatrics  
University of Missouri - Kansas City School of Medicine

## Eric Rush, MD, FAAP, FACMG

Clinical Geneticist  
Children's Mercy Kansas City  
Associate Professor of Pediatrics  
University of Missouri-Kansas City School of Medicine

## Overview and Target Audience

All medical professionals caring for children or adults with Ehlers-Danlos Syndromes (EDS), Hypermobility Spectrum Disorders (HSD) and their complex conditions.

### Clinical Attendees Course Description:

Many medical disciplines encounter patients with EDS, HSD and frequent co morbidities including autonomic dysfunction (postural orthostatic tachycardia syndrome and orthostatic intolerance), mast cell activation syndrome, gastrointestinal disorders and chronic pain. Despite recent advances in EDS diagnostic criteria and care, misunderstandings regarding these conditions are prevalent and EDS remains under recognized. Ehlers-Danlos Syndromes are a group of connective tissue disorders that vary in their genetic cause and expression. Patients often present with varying degrees of complex symptoms across numerous specialty areas and endure significant diagnostic delays. Early diagnosis and treatment is critical for increased quality of life and reduced medical and emotional impacts. The latest in diagnosis and care will be presented for pediatric and adult patients. The target audience includes primary care providers, specialists and allied health professionals.

## Patient/Family Attendees

Patients and families with Ehlers-Danlos Syndromes and related disorders will increase their understanding of EDS and its potential challenges. They will learn treatment options and get ideas for improving overall quality of life. This increased understanding will help them better navigate care for those impacted by EDS.

The lectures are geared for adult patients and pediatric patient family members. Pediatric patients must be twelve or older to attend the seminar.

## Continuing Education Credit

**CME:** Children's Mercy Hospital is accredited by the Missouri State Medical Association to provide continuing medical education for physicians.

Children's Mercy Hospital designates this live educational activity for a maximum of **7.5 AMA PRA Category 1 Credit(s)™**. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

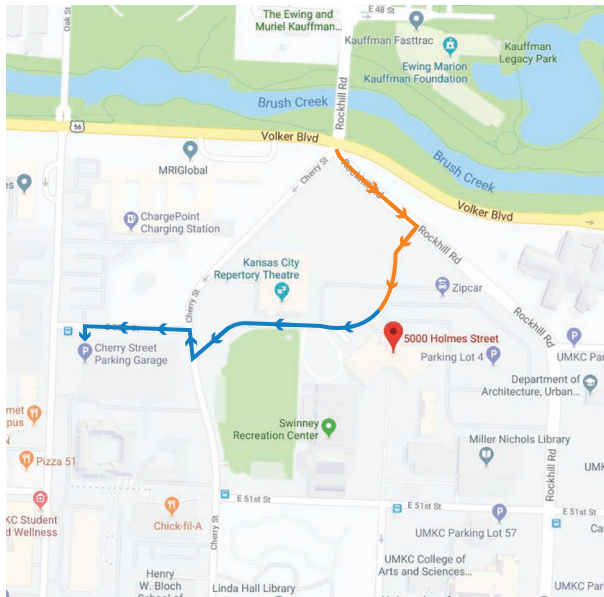
**Others:** A general certificate of attendance will be given to all other healthcare providers.

## Continuing Education Objectives

Upon completion of this conference, participants should be able to:

- Discuss the positive and negative aspects of the 2017 EDS International Classification, the new classification system for EDS.
- Describe the utility of molecular testing in Ehlers-Danlos Syndromes and related connective tissue disorders.
- Explain the connection between different conditions associated with EDS, including musculoskeletal, GI, neurological and dysautonomia.
- Explore patient-centered management for EDS related concerns.
- Define the relationships between GI symptoms and EDS/joint hypermobility & orthostatic intolerance (OI).
- Identify cardiac abnormalities associated with EDS.
- Describe differences between conventional physical therapy interventions and EDS-focused physical therapy.
- Identify the mechanism of pain and loss of function in EDS.
- Describe chronic pain in EDS and musculoskeletal disorders and identify current treatment options for chronic pain.
- Describe the three major forms of disordered mast cell activation.
- Describe the concept of Occult Tethered Cord.





## Seminar Location

The seminar will be held at the University of Missouri-Kansas City Volker campus in the Pierson Auditorium in the Atterbury Student Success Center.

**5000 Holmes Street  
Kansas City, Missouri 64110**

## Parking

Seminar parking is free and available at two locations

Park in the Cherry Street Garage located at 5005 Oak Street, Kansas City, MO 64112. From the 5th floor level, take the Northeast Tower covered walkway, pass the Durwood Soccer Stadium and cross the street to the Atterbury Student Success Center on the right. From the front steps of the building, take the stairs or elevator up to the 2nd floor to Pierson Auditorium.

Those needing closer access to Pierson Auditorium may park in any of the parking lots near the Atterbury Student Success Center. All parking spaces are available (Student Permit, Faculty/Staff Permit, or Metered) except for those reserved for a special purpose (such as Dean's spots or UMKC Vehicle spots). State-issued handicap placards or plates may be used to park in any designated handicap accessible spots.

To avoid stairs or the small elevator, a wheelchair accessible entrance directly to the Pierson Auditorium is located at the back entrance off the large circle drive located West of Atterbury Student Success Center.

For maps please visit <https://www.edskc.org>

## Acknowledgments

\*As of date of publication

We gratefully acknowledge the generous financial support from the following sponsors:

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### EDSKC Collaboration Inc. Board Members and Staff

Wendy Cogan, BSN

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## Registration

SPACE IS LIMITED!

Visit our website today to register online at <https://www.edskc.org>

You will receive confirmation and other important details via the online registration system. Registration and ticket purchase will be completed through Eventbrite.com after visiting [edskc.org](https://www.edskc.org).

## Fees

Physicians (CME) ..... \$150

Nurses/PTs/Other Allied Health.....\$85

Patient/Family Member .....\$35

\*Each family member must register separately

Registration fees include box lunch and snacks, CME for physicians and certificate of attendance for nurses and other allied health professionals.

**Payment options:** Online via credit card only at <https://www.edskc.org>

## Cancellation

No refunds will be granted for non-attendance, although you may send a substitute. The Planning Committee reserves the right to alter the agenda as necessary. In the event of unforeseen circumstances, the Planning Committee reserves the right to cancel the seminar with a refund to the participant.

## Further Information

For questions, you can email us at [info@edskc.org](mailto:info@edskc.org)

Register at  
[www.edskc.org](https://www.edskc.org)

