

GLOBAL LEARNING CONFERENCE DUBLIN 2023

# DIFFICULT CONVERSATIONS IN EDS & HSD

PRESENTATION

**DECONDITIONING:  
How to appropriately recondition  
the hypermobile body**

SPEAKER

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Muscle & Joint Clinic, Clinical Director**



**GLOBAL  
LEARNING  
CONFERENCE**  
DIFFICULT CONVERSATIONS  
IN EDS & HSD

DUBLIN  
ireland  
#

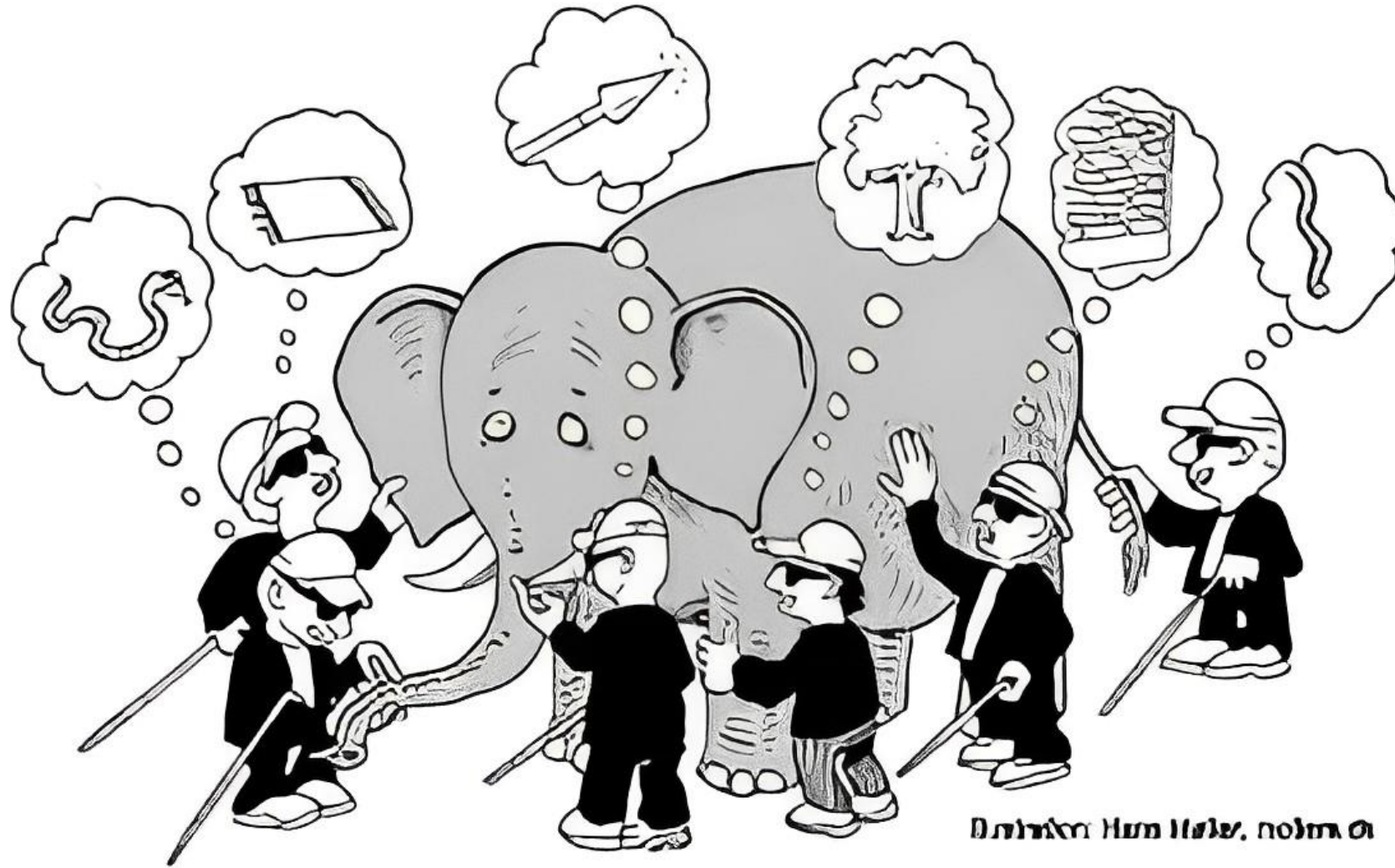
I Have No Disclosures

## Disclosure Page



# The Challenge OF EDS

What Part Of The Elephant Is The Clinician Considering?



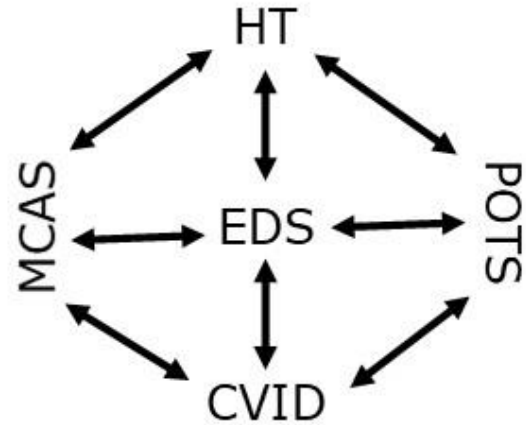
# EDS is a Bigger Elephant than Most Practitioners Encounter



Gastrointestinal complications of the Ehlers-Danlos Syndrome. Peter H. Beighton, J. Lamont Murdoch, Theodore Votteler. Gut, 1969, 10, 1004-1008

Non-musculoskeletal symptoms in joint hypermobility syndrome. Indirect evidence for autonomic dysfunction? Rheumatology (Oxford). 2004 Sep;43(9):1194-5.

## The EDS Elephant: Defined (Abridged)



MCAS: Mast Cell Activation Syndrome

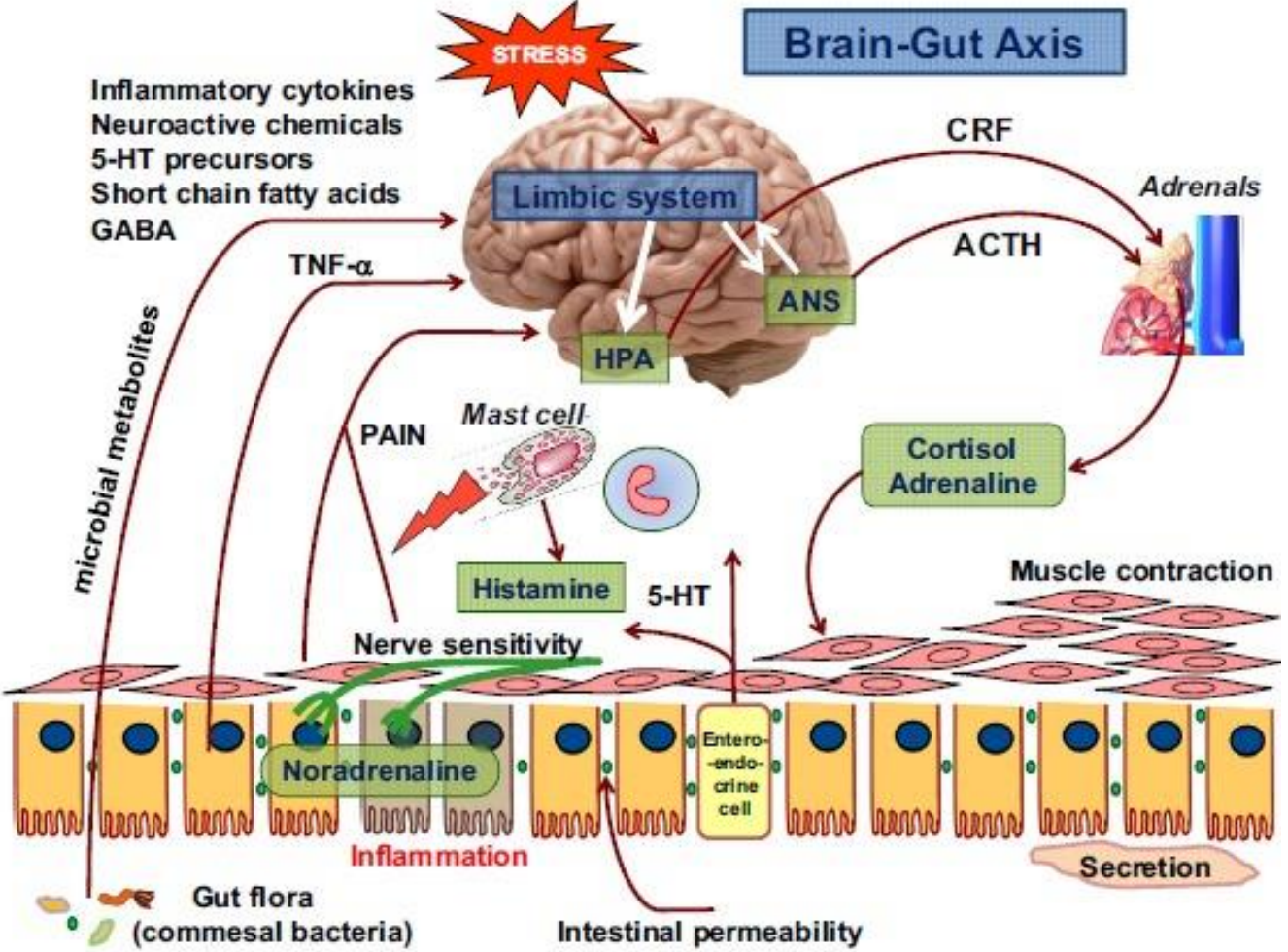
CVID: Common Variable Immune Deficiency

HT: Hashimoto's Thyroiditis

POTS: Postural Orthostatic Hypotension Syndrome



# Physical – Emotional – Chemical (PEC)



## Physical – Emotional – Chemical (PEC)



### ANS upregulation

Eccles, J., Beacher, F., Gray, M., Jones, C., Minati, L., Harrison, N., Critchley, D., Brain structure and joint hypermobility: relevance to the expression of psychiatric symptom, *Br J Psychiatry*. 2012 Jun; 200(6): 508–509.

De Wandele, Rombaut, Leybaert, Van de Borne, De Backer, Malfait, De Paepe, Calders, Dysautonomia and its underlying mechanisms in the hypermobility type of Ehlers–Danlos syndrome

*Seminars in Arthritis and Rheumatism* 44 (1), August 2014, Pages 93-100

Seneviratne, S., Maitland, A., Afrin, L Mast cell disorders in Ehlers–Danlos syndrome *Am J Med Gen* <https://doi.org/10.1002/ajmg.c.31555>

## Physical – Emotional – Chemical (PEC)



### Excitatory

### Biometrics

- Pulse - POTS
- Pupillary diameter - hard to measure
- Gastroparesis - does it determine cause frequently?
- Muscle tone - deconditioning
- HRV - definitive, accurate, well established
  - Cheng, Y-C., Su, M., Liu, C/, Huang, Y., Huang, W. Heart rate variability in patients with anxiety disorders: A systematic review and meta-analysis. *Psychiatry Clin Neurosci* 76(7):292-302. doi: 10.1111/pcn.13356.



## Strain Is Good, In the Right Amount

### Strain and Recovery

- HRV
  - Window Into ANS
  - Readily Accessible
  - Easy to Understand
- Set different targets for different levels of deconditioning

### Case Study

- Musician
- 94% Symptom Decrease
- 8 Months



## Summary

EDS/HSD is a whole-body disorder

- Physical
  - Strain & Recovery
- Chemical
  - MCAS
  - CVID
  - POTS
- Emotional
  - Joint Instability
  - Neuroplasticity

Jiggly Body = Jiggly Brain



## Hippocratic Oath Starts With Words

# Words can harm, words can heal

## “First Do No Harm”

World Medical Association General Assembly on October 14, 2017

I SOLEMNLY PLEDGE to dedicate my life to the service of humanity;

THE HEALTH AND WELL-BEING OF MY PATIENT will be my first consideration;

I WILL RESPECT the **autonomy and dignity** of my patient;

I WILL MAINTAIN the **utmost respect for human life**;

I WILL NOT PERMIT considerations of age, **disease** or **disability**, creed, ethnic origin, **gender**, nationality, political affiliation, race, **sexual orientation**, social standing, or any other factor to intervene between my duty and my patient;

I WILL RESPECT the secrets that are confided in me, even after the patient has died;

I WILL SHARE my medical knowledge for the benefit of the patient and the advancement of healthcare;

I WILL NOT USE my medical knowledge to violate human rights and civil liberties, even under threat;



# Elephants and Zebras Help Each Other In The Wild



And In Life



Thank you  
for listening