

three exciting findings in ehlers-danlos research & takeaways for your health

bo forbes, psy.d., C-IAYT

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yoga as mind-body medicine

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defining ehlers-danlos syndrome
+ the larger picture behind it

defining ehlers-danlos syndrome (EDS)

- EDS: 13 heritable (genetic) connective tissue disorders
- in 2017, change in criteria—another coming up at end of 2026
- they share genetic mutations that disrupt collagen synthesis + processing as well as stability of extracellular matrix
- mutations cause joint hypermobility, skin fragility, vascular complications
- hypermobile EDS (h-EDS) has **no** known inherited genetic marker*
- historically classified by musculoskeletal issues, e.g., joint dislocations, hypermobility, hyperextensibility, soft tissue injuries, skin fragility/elasticity
- but this is a limited way to understand connective tissue and EDS
- EDS affects multiple neurobiological + neurological systems
- **huge** overlap with issues in the following systems: gastrointestinal, immune, vascular, autonomic + central nervous systems, & **sensory integration***

but what is the larger pattern behind EDS?

we're living in a viral world



over 200 viruses cause disease in humans

some encode their genomes as DNA,
and some as RNA,
which allows for rapid mutation

HIV

ebola

MERS

Zika

many influenzas

hepatitis

coxsackie (causes hand, foot, mouth disease)

SARS-CoV-2

what is epithelium?

- type of tissue that forms cover (barrier) for all outer + inner body surfaces
- lines body cavities and hollow organs: throat, gut, and more
- four basic types of tissue:
 - epithelial tissue
 - connective tissue
 - muscular tissue
 - nervous system tissue
- all substances that enter or exit an organ must cross epithelial tissue
- outer layer of skin, gut lining, respiratory tract lining, sweat glands, blood vessels, blood-brain barrier, eye, throat, and more
- main border between parts of body and between body + world
- connective tissue + epithelial tissue share nutrients and support

RNA viruses often attack epithelial barriers

gut lining

blood vessels

gut-blood barrier

blood-brain barrier

skin and even neural networks

Going Viral: Long Covid Unmasks EDS

- study used data from 23 million patients across the U.S.
- looked at correlations between h-EDS, Covid-19 infection, Long Covid, & related chronic conditions like CFS/ME
- rates of getting Covid-19 similar between people with h-EDS + matched controls
- **but** people with h-EDS were much more likely to develop Long Covid
- risk highly elevated among h-EDS patients with overlapping conditions:
 - post-viral syndromes
 - postural orthostatic tachycardia syndrome (POTS)
 - dysautonomia (autonomic nervous system dysfunctions)
 - immune dysregulation, including mast cell related symptoms (GI + systemic)
 - chronic fatigue
- people with POTS, mast cell issues, or CFS had highest rates of Long Covid

(Pearson, M., Laraway, B., & Haendel, M., et al., [Can Covid Unmask EDS + HSD](#), 2025)

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in my all-day on
chronic post-viral issues like Long Covid,
i suggested a “systems” way of understanding
Long Covid, CFS/ME, chronic pain syndromes,
autoimmune disorders, inflammatory diseases,
even depression + ADHD

we might see them as vulnerabilities/injuries to
the body's multiple barriers

EDS + public health issues

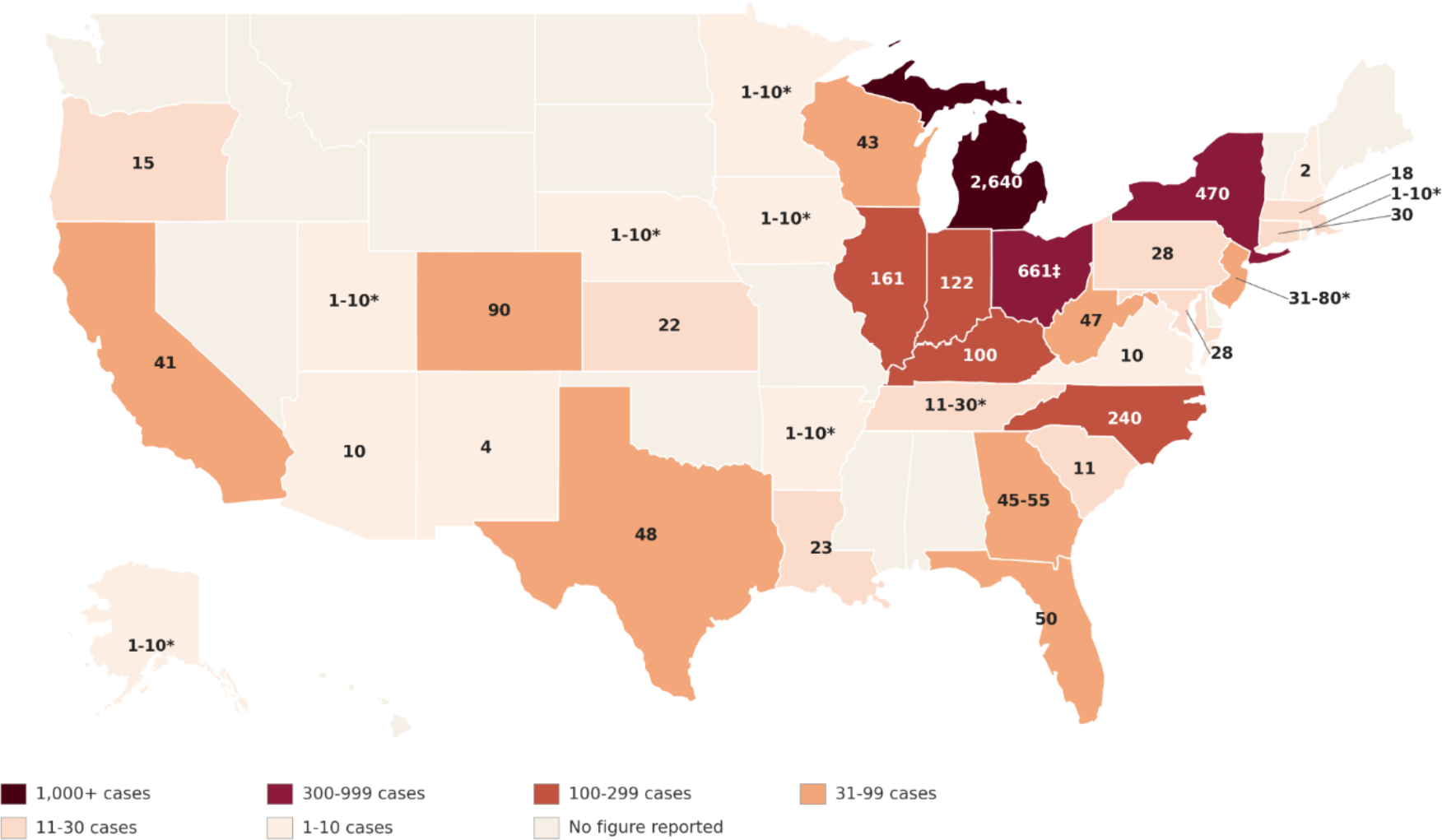
people with EDS often have paradoxical
responses to anesthesia + medications

- 3x as resistant to local anesthesia
- opioid resistance
- blood pressure drops
- histamine response to opioids

Reported Cyclosporiasis Cases

5,008+ combined cases across 35 reporting states · As of July 13, 2026
* Reported by CDC · ‡ NW Ohio (Lucas County) reports 661; Ohio Dept. of Health statewide total is 365

health security
operations center



Not all reported cases constitute outbreaks and not all cases are domestically acquired. Case report dates vary by state.

Figure 1. Cyclosporiasis cases reported by state as of July 13, 2026 | HSOC analysis

food-borne outbreak in the U.S.

- microscopic parasite called **cyclospora**
- lives in human gut, specifically small intestine
- parasites burrow into intestinal lining and reproduce
- they cause inflammation and trigger watery diarrhea
- spread through food or water contaminated with human feces
- is shed in stool as a tough shell, but is not contagious in normal ways
- needs 1-2 weeks to mature before it can infect someone else
- if you have diarrhea for more than two days, request a specific test
- cyclospora panel is not in most standard stool tests
- eggs shed from body inconsistently: you may need as many as 3 tests spaced 24 hours apart to make an accurate diagnosis
- take Bactrim or Septra (antibiotic) for ten days
- people with EDS need to avoid fluoroquinolones

fluoroquinolones contraindicated in EDS

- class of antibiotics that includes:
 - ciprofloxacin (Cipro)
 - levofloxacin (Levaquin)
 - moxifloxacin (Avelox)
 - Ofloxacin (Floxin)
 - Gemifloxacin (Factive)
 - Norfloxacin (Noroxin)
- these are often prescribed for respiratory, urinary tract, and skin infections
- linked to adverse side effects, e.g. in musculoskeletal + connective tissue
- this is especially true in vascular EDS (high risk of arterial + organ rupture)
- tendonitis, tendon rupture, aortic aneurysm or dissection
- also GI issues + peripheral neuropathy
- fluoroquinolones can harm any place that connective tissue vulnerabilities can impact, including blood vessels, gut lining, etc.

EDS + its associated disorders are
multi-system health issues

most advanced treatment centers are
concierge or private functional medicine practices,
making treatment yet another
health care inequity

EDS + the gut-brain axis

overlap between EDS + gut-brain disorders

- study: 1,044 people with hypermobile EDS (h-EDS) and HSD
- 87.8% female, mean age 42
- findings: two main clusters of disorders of gut-brain interaction
- cluster 1: functional dyspepsia, dysphagia (swallowing issues), functional heartburn, belching (often excess acid reflux), chronic nausea + vomiting, IBS
- cluster 2: predominantly IBS
- gut disorders hugely elevated in EDS in general
- Canadian study
- abdominal pain most highly reported
- disorders of gut-brain interaction such as IBS are, too

(Choudhary, A., Aziz, I., and Aziz, Q., et al., [h-EDS, HSD, and Disorders of Gut-Brain Interaction](#), 2025)
Abu-Faraneh, E., Tse, Y., Parker, C., & Liu, L., [Prevalence of Gut Disorders in EDS](#), 2023)

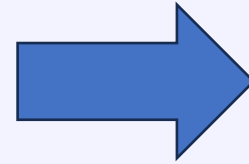
EDS + the immune system

EDS + mast cell activation syndrome (MCAS)

- MAST cells are body's first responders
- they don't hang out in bloodstream but are frontline sentinels in high-impact areas exposed to world: skin, mucosal lining of gut, lungs, nasal passages, just outside blood vessels, lymph vessels; they're in every organ
- they adjoin every neuron in peripheral and central nervous systems
- people with MCAS have mast cells that misfire at inopportune times
- brain fog, hives, palpitations, postural orthostatic tachycardia syndrome
- cause said to be acquired changes in genes that regulate mast cells
- high baseline level of activation, over-response to non-threatening stimuli
- big variability: some have funky MAST cells in gut, others in skin or lungs
- huge overlap with Ehlers-Danlos syndrome, POTS, CFS/ME
- diagnostic: test for blood levels of tryptase (enzyme found in mast cells)*

EDS + sensory awareness

note the extra info
on the following slides



sensory + motor status in EDS + hypermobility

- interoception: capacity to receive, interpret, and respond to, regulate signals that come from the body
 - enteroception: in the gut
 - cardioception: with the heart
 - also muscle
- proprioception: internal GPS, ability to sense the space around us and awareness of movement
 - also relates to the capacity for exploration of movement and the world, plus new movements, plus playfulness
- body agency: the capacity to act on an intention and to perceive the impact we have on the world around us
- body ownership: the sense we have that our bodies belong to us
- vestibular awareness: our sense of balance, ground, and capacity to be **out** of balance + tolerate that (related also to vertigo)
- peripersonal space: regulating the space between us + others (boundaries)
- **any or all of these can be dysregulated in EDS + can be therapeutic tools**

One of the questions from today centered on the relationship between EDS and trauma and dissociation. The connections are there, but perhaps “looser” (pun intended) than some of the others we made together.

The article states, “When it comes to exosomes, there’s something else at work here: they are the smallest unit of **extracellular vesicles**, membrane-bound particles released into the environment surrounding the cells by every type of cell known today, including neurons, epithelial cells, immune cells, stem cells, platelets and cancer cells.” (Note the epithelial cells, neurons, and immune cells.)

Exosomes play a role in autoimmune connective tissue diseases such as rheumatoid arthritis, Sjogren’s Syndrome, inflammatory arthritis, and lupus. And these disorders overlap strongly with EDS and hEDS.

The next slide links to my recent Substack on the gut barrier. It mentions a study by Tracy Bale and her colleagues at the University of Colorado. The study looked at women who experienced sexual assault and broke the participants up into three groups. The first were assaulted before the age of 14, the second between the ages of 14 and 17, and the third were assaulted at 18 or older.

Sexual assault, particularly in the vulnerable developmental window of adolescence between ages 14 and 17, causes a premature aging process at the level of the skin. It specifically impacts Merkel cells—which detect light touch and relay touch information to mechanoreceptors—part of both interoception and exteroception—and exosomes.

The exosomes mentioned in the study carry inflammation throughout the body, conveying it across barriers and therefore, systems. They are part of the overlap between autoimmune issues and EDS and now, trauma and EDS.

Women who experienced sexual violence between 14 and 17 show unique changes in exomes, extracellular vesicle proteomes (proteins), and circulating mitochondrial DNA. Sexual trauma during that key developmental window reprograms the skin, the body's primary boundary between self and world, and triggers a premature aging process of the skin, **the boundary between self and world**, at the molecular level.



extra reading
gut barrier health
+ the

[click here](#)

[the relevant section](#)

