Understanding *EDS & HSD*

What are EDS & HSD?

The Ehlers-Danlos syndromes (EDS) are a group of 13 genetic connective tissue disorders affecting the skin, joints, and blood vessels. Hypermobility Spectrum Disorder (HSD) presents with joint hypermobility and related symptoms but does not meet the full criteria for hypermobile EDS (hEDS).

Hypermobile Ehlers-Danlos Syndrome (hEDS)

hEDS is the most common subtype, inherited in an autosomal dominant pattern. Unlike other EDS types, hEDS does not currently have a known genetic marker.

Common Symptoms:

- **Joint Hypermobility: Unusual flexibility, joint instability, subluxations, and dislocations.**
- **Skin Changes: Soft, stretchy skin, easy bruising, and slow wound healing.**
- **Chronic Pain & Fatigue: Widespread pain, joint pain, and persistent exhaustion.**
- **Cardiovascular Issues: Mitral valve prolapse, aortic root dilation.**
- **Gastrointestinal Issues: IBS-like symptoms, delayed gastric emptying.**
- **Laryngological Issues: Dysphonia, dysphagia, hoarseness, vocal cord hemorrhage.**
- **Dysautonomia: Dizziness, fainting, and temperature regulation issues.**

Common Co-morbidities:

- **Neurological & Nervous System Issues: Cervical or craniocervical instability, Chiari malformation, tethered cord syndrome, and peripheral neuropathy.**
- **Immune and Allergic Disorders: Mast cell activation syndrome, immune dysfunction**
- **Musculoskeletal & Structural Issues: TMJ dysfunction, scoliosis, flat feet, pelvic organ prolapse, visceroptosis**
- **Cardiovascular Issues: Postural orthostatic tachycardia syndrome (POTS)**
- **Gastrointestinal & Bladder Disorders: Gastroparesis, IBS, SIBO, eosinophilic esophagitis & interstitial cystitis.**
- **Vascular Compression Syndromes: Thoracic outlet syndrome, median arcuate ligament syndrome (MALS), nutcracker syndrome, superior mesenteric artery syndrome (SMAS)**

Diagnosis & Testing:

hEDS is diagnosed based on the 2017 International Classification of the Ehlers-Danlos Syndromes criteria:

1. **Generalized Joint Hypermobility (Beighton Score test)**
2. **Additional Symptoms & Comorbidities**
3. **Exclusion of Other Conditions (e.g., Marfan Syndrome, Lupus)**

Why Early Diagnosis Matters:

- **Provides guidance on symptom management**
- **Helps prevent complications like joint damage & cardiovascular issues**
- **Allows access to tailored treatments & support networks**

Management & Treatment:

Although there is no cure, symptom management strategies include:

- **Physical Therapy: Strengthening muscles to stabilize joints**
- **Pain Management: Medications, bracing, and lifestyle modifications**
- **Cardiac Monitoring: Regular echocardiograms if necessary**
- **Gastrointestinal Support: Specialized diets, hydration, and medications**

What Providers Could You See for EDS?