

EHLERS-DANLOS SYNDROMES (EDS) ARE A TOP CAUSE OF IPS

About 10 to 12 years ago patients with EDS began entering our intractable pain (IP) program. Many had “strange” and “migrating” pain sources. At that time, Ehlers Danlos Syndrome (EDS) was known as either a dermatological or pediatric condition, but never a “pain problem.” Benign hypermobility, now referred to as hypermobile EDS (hEDS), was thought, until recently, to be an innocuous problem affecting only joints. Recent research has identified 13 types of EDS, and we have found it is among the top 3 most common causes of IPS. No form of EDS can be considered “benign” anymore. The syndrome itself is a rare genetic disease among adults, and it is still hardly recognized in medical textbooks.

MAJOR DISCOVERIES

Our first discovery was that the EDS patients who had IPS, also had serious neurologic complications including: adhesive arachnoiditis (AA), spinal fluid leaks, Chiari symptoms, Tarlov cysts, herniated discs, and cauda equina inflammatory disorder. At that time there were no referral sources, and no recommended treatment except symptomatic pain medicine and exercise. A sad discovery was that no one, until recently, seemed to take the disease seriously. Many medical writings still state it is merely a nuisance disease that doesn’t cause significant disability or shorten life span. From our observations of patients, we found this to be blatantly not true.

HOW EDS CAUSES IPS

- #1. EDS and related disorders have a genetic defect in collagen production which leaves connective tissue, especially in the spinal canal, with a fragile, poorly supportive tissue fabric.

- #2. Stress incidents like an injury, infection, or chemical insult may cause defective collagen to dissolve, fail to regrow (disappear), and lead to neurologic complications. Skin biopsies show loss of nerve fibers and MRI’s of the spinal canal show tissue abnormalities.

- #3. Defective collagen, especially when stressed, may dissolve leaving weakened tissue that develops micro-tears, inflammation, severe pain, and IPS.

TREATMENT OF THE DUAL DISORDERS EDS & IPS

The dual disorders of (EDS & IPS) requires treatment with an aggressive 3 component medical program:

- * Inflammation reduction
- * Tissue repair
- * Pain control

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