

EDUCATIONAL UPDATE

Ehlers Danlos Syndrome (EDS)

Are a group of genetic connective tissue disorders.

Symptoms may include loose joints, joint pain, stretchy skin, and abnormal scar formation. These can be noticed at birth or in early childhood. Complications may include aortic dissection, joint dislocations, scoliosis, chronic pain, or early osteoarthritis.

Musculoskeletal symptoms include hyperflexible joints that are unstable and prone to sprain, dislocation, subluxation, and hyperextension. There can be an early onset of advanced osteoarthritis, chronic degenerative joint disease, swan-neck deformity of the fingers, and Boutonniere deformity of the fingers. Tearing of tendons or muscles may occur. Deformities of the spine, such as scoliosis (curvature of the spine), kyphosis (a thoracic hump), tethered spinal cord syndrome, and occipitoatlantoaxial hypermobility may also be present. There can also be myalgia (muscle pain) and arthralgia (joint pain), which may be severe and disabling. Trendelenburg's sign is often seen, which means that when standing on one leg, the pelvis drops on the other side. Osgood–Schlatter disease, a painful lump on the knee, is common as well. In infants, walking can be delayed (beyond 18 months of age), and bottom-shuffling instead of crawling occurs.

Facts about EDS:

1. "Ehlers Danlos is a genetic metabolic biosynthesis dysfunction caused by deficiencies in all of our signaling growth factor molecules of the cells of all the layers of our connective tissues that are responsible for producing connective tissue. It's not just the collagen that has the deficiency. It's all the different layers that make up all of our organs systems. Without these signaling factors there is a disruption in communication between these cells. This creates a DNA/RNA dysfunction so that the instructions for connective tissue production cannot be executed

- 2. Did you know that the dura and arachnoid villi of the brain contain connective tissue collagen type I and III ? In some with EDS, the dura is weakened and the arachnoid villi become inefficient.
- 3. Our connective tissue cells which are responsible for creating our collagen, fibrils, elastin need very specific molecules for them to function properly. Each cell of each individual connective tissue collagen has different needs within the molecules of them. Humans are created to convert the foods we eat into the specific molecules for each cell via biosynthesis.
- 4. "Science: Connective tissue collagen is not only in our ligaments and tendons of our joints but also makes up parts of many other organ systems. All of these are compromised in EDS.
- 5. Connective tissue collagen type I and type III make up the structural integrity of the vascular system, the tiny tendons supporting our heart valves, the dura and arachnoid villi, and the ligaments of pelvic organs. How is collagen produced? fibroblast are responsible for connective tissue collagen production.
- 6. Copper deficiency and EDS: With or without Ehlers Danlos Syndrome, you can't make strong collagen if you are copper deficient. Estimates are as high as 80% of Americans are copper deficient. MitoSynergy copper supplement has been considered an important supplement for those people. Its the only safe bioavailable copper supplement. It's antibacterial and antifungal and the only patented treatment for lyme disease. It kills any bad bacteria anywhere in your body including lyme and coinfections.
- 7. Farmers stopped adding <u>copper</u> back into soils over 50 years ago so we cant get copper from foods. Liver used to be a good source but if the cow didnt eat grass and grain grown in copper rich soil then the liver has no copper. And if you dont make enough ceruloplasmin you can't process copper in foods anyway. More information about copper, lyme and EDS is available in the Bioavailable Copper group. Other copper supplements and injections are toxic metallic and accumulate in your brain and liver tissues so please dont substitute other brands and forms.
- 8. Fibromyalgia, demyelination of peripheral nervous system, insufficient connective tissue myelin of peripheral nerves, electric shocks, pin pricks, electro-hypersensitivity. EDS causes the peripheral nerve

connective tissue myelin to thin and weaken. This causes nerves to become overactive and allows electric signals to escape. This can cause fibromyalgia symptoms with severe pain, extreme fatigue, low stamina and electric shock/pin prick sensations. Many who have demyelination secondary to EDS also suffer from electro-hypersensitivity. Important to know <u>D-ribose</u> is given as a supplement to re-myelinate the peripheral nerves and eliminate electro-hypersensitivity and fibromyalgia symptoms. There are patients with fibromyalgia that say: ."After starting <u>D-ribose</u> the symptoms disappeared and energy returned. This is a lifelong daily treatment and if stopped symptoms will return."

- 9. To counteract this dysfunction we need to supplement our bodies with NGF, nerve growth factor. Lions Mane Mushroom has what our central nervous system needs to stimulate oligodendrocytes to increase the connective tissue production of this very important organ system (CNS) and eliminate symptoms. Please know the connective tissue of the central nervous system is different from the connective tissue of the peripheral nervous system. I already have D-ribose on the protocol to restore the connective tissue of the peripheral nervous system. So, to restore the connective tissue of the CNS (central nervous system) Host Defense Lions Mane freeze dried mushroom capsules 1 to 2 daily is needed.
- 10. There is a list of supplement that is very helpful in these patients, called <u>Cusack Protocol</u> (look it up). <u>Prolotherapy</u> is very successful in treating loose ligaments and pain in these patients.

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