EDS Foundation

Engaging the Canadian Health Care System in the Diagnosis & Treatment of EDS: 5 Steps

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1) The Family Doctor should look for basic criteria to diagnose EDS: dislocations, subluxations, loose joints, falls, ruptured ligaments, bruises, stretchy skin, neuro-musculo-skeletal visceral pain, digestive and urogenital issues, pectus carinatum or excavatum, sacral dimple and lump, defective heart valves, droopy eyelid, etc. (see References 1 - 7). If the patient and family members present these, then the family doctor should refer the patient to a specialist, such as a neurologist, rheumatologist, PT, OT, etc.

2) The Family Doctor and/or Specialist should use the Beighton Score and Brighton Criteria (see 1 – 4, 7) to further diagnosis EDS (fast and cheap since no equipment required). If the patient presents the symptoms of these 2 scales, the family doctor and/or specialist should order tests such as an x-ray, CT Scan, MRI, EMG, nerve conduction, etc.

3) The Radiologist should be trained to interpret these tests. Canadian radiologists currently do not recognize some major problems associated with EDS craniocervical and/or cervical

instability, and tethered cord syndrome. For example, a radiologist who reviewed a patient's neck flexion-extension x-ray in 2013 wrote on 2 lines that the patient had NO craniocervical instability. However, in Maryland the CT Scan, MRI and neurosurgeon reports (2 pages each) indicated that the patient had Severe Craniocervical instability (her neck was unable to hold her head properly, her head was bouncing while walking or on the bus, and hitting the car headrest even if she pushed as hard as she could against it)

4) If the specialist finds EDS symptoms and the radiologist reports dislocated vertebrae, craniocervical and/or cervical instability, sacral lamp and dimple that are physical markers for tethered cord, etc. (see 5 - 6) then the specialist should refer the patient to a Geneticist to confirm the diagnose and genetic counseling

5) The Geneticist can confirm an EDS diagnosis and in consultation with other specialists refer the patient for appropriate treatment such as PT, OT, cardiologist, gastroenterologist, neurologist, different surgeon for different needs, etc. See 1 – 7.

References

1.- EDS Diagnostics 2017

https://www.ehlers-danlos.com/eds-diagnostics/

2.-EDSociety Diagnostic Checklist for hEDS

https://www.ehlers-danlos.com/wp-content/uploads/hEDS-Dx-Criteria-checklist-1-Fillable-form.pdf

https://www.ehlers-danlos.com/wp-content/uploads/hEDS-Dx-Criteria-checklist-1.pdf

3.-EDSociety Diagnostic Checklist for al 13 subtypes

https://www.ehlers-danlos.com/eds-types/#top

4.-HSD vs. hEDS: The New Diagnostic Criteria. The article says If someone was diagnosed with hEDS before the 2017 criteria, there's no cause to seek a new diagnosis unless they decide to participate in new research or need to be reassessed for some other reason., https://ehlers-danlos.com/wp-content/uploads/hEDSvHSD.pdf

5.-2017 EDS International Classification – see all articles

https://www.ehlers-danlos.com/2017-eds-international-classification/

6.-2017 EDS International Classification for Non-Expert – see all articles

https://www.ehlers-danlos.com/2017-eds-classification-non-experts/

7.-ASSESSING JOINT HYPERMOBILITY –

https://www.ehlers-danlos.com/assessing-joint-hypermobility/ -> Scroll down to the end