

Suggested medical work-up for those traveling to see Ehlers Danlos specialists.



The following information was agreed upon by physicians who attended the 2014 TCAPP Physician Think Tank on Ehlers Danlos Syndrome (EDS) and Co-Morbid Conditions. This worksheet is only a guide for patients (and their local physicians) who are traveling to see an EDS specialist. This guide is not meant to take the place of, or to override the recommendations of one's primary care physician. The goals of this guide are to help traveling patients keep as much of their medical care and work-up with their local physicians; aide the patients in lessening their financial costs by doing as much of their medical work-up at home as they are able; and when travel is necessary, help the patient collect as much medical information in advance to make the most out of a consult with the EDS specialist.

A. Documents to bring with you when traveling to any type of specialist:

- Results of any previous genetic testing
- List of all your physicians
- Chronological summary of medications tried and reactions

B. Suggested medical work-up prior to seeing an EDS medical specialist (internist, cardiologist, neurologist, etc.):

- Echocardiogram and cardiology evaluation for symptoms of POTS
- Eye exam
- Polysomnography (sleep study)
- Comprehensive chemistry panel
- CBC with differential
- TSH levels
- ANA
- Sedimentation rate
- Ferritin levels
- Vitamin B12 and Vitamin D25 OH levels
- Tryptase levels (if any allergy signs)
- DHEA, free and total testosterone serum and urine osmolality
- Pharmacogenetic work-up (such as one by Genelex, <http://genelex.com/patients/>)

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C. If seeing an EDS geneticist specialist, in addition to as much of A and B, also bring the following:

- Assessment by any doctor that one may have EDS if they meet the following criteria:
 - Multiple Joint Hypermobility (3 or more joints), for more than 3 months
 - Symptoms of dysautonomia (POTS, gastroparesis, other)
 - Chronic pain
 - Chronic fatigue
 - +/- Delayed wound healing
 - +/- Hyperelasticity of skin
- History of any connective tissue disorder, such as: dissections, aneurysms, organ rupture
- Obtain a thorough family history
- Outline information in relation to the patient's symptoms

D. If seeing a neurosurgeon for possible Spinal Ehlers Danlos complications, obtain, if possible:

- MRI of the brain (to rule-out MS, brain tumors, others)
- MRI of the C-Spine in flexion and extension (upright MRI if possible)
- MRI of the L-Spine
- Urodynamics (if able and clinically relevant)
- CT Rotational Scan (CT of Cervical Span straight/neutral and at a 90 degree angle in both directions – may reduce to one direction to decrease radiation exposure)