

Ehlers Danlos Hypermobility Referral Letter revised 9-23-24

Dear Referring Provider,

We receive hundreds of referrals for this indication each year, mostly out of concern for hypermobile Ehlers Danlos syndrome (hEDS). The diagnostic guidelines for hEDS have been updated recently and we have altered our referral process in response.

- Hypermobility referrals now **require** a Beighton score. Information on Beighton score can be found at [Assessing Joint Hypermobility - The Ehlers Danlos Society \(ehlers-danlos.com\)](https://ehlers-danlos.com). Please complete this prior to referral, as this metric defines hypermobility.
- Any patient who scores **less than a 6/9 will not be eligible to be evaluated.**
- The new 2023 diagnostic guideline for hEDS precludes diagnosis before skeletal maturity is reached. **If you refer a patient who is not yet skeletally mature, they cannot be diagnosed with hEDS.**
- Younger patients may qualify for a diagnosis of "pediatric generalized joint hypermobility" or "pediatric hypermobility spectrum disorder" with subtypes of skin involvement, core comorbidities, musculoskeletal involvement, or a combination of the above.
- **Additionally, family history is no longer used as a diagnostic criterion**, so family history of hypermobility has no bearing on diagnosis.
- **Patients should not be referred for family history of hypermobility or hEDS alone.** ***If the patient's history or family history is suggestive of another type of connective tissue disorder, please indicate that in your referral documentation so we can best ensure that all patients receive the optimal level of care.