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Deputy Sean Fleming TD
Dáil Éireann
Leinster House
Dublin 2

PQ No. 5316/20

To ask the Minister for Health his plans to introduce a specialist to deal with Ehlers-Danlos syndrome and hypermobility spectrum disorder; and if he will make a statement on the matter.

Dear Deputy Fleming,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for Health for response. I have examined the matter and the following outlines the position.

Response:

Ehlers Danlos syndrome (EDS) is a rare disease. The principal clinical manifestation is hypermobility/hyperelasticity of soft tissues particularly joints and the medical discipline of Rheumatology provides a lead role in the diagnosis and management of patients with EDS. Most patients suffer from hypermobile joints and skin which is managed mainly within primary care services once the diagnosis is confirmed. Where patients have severe EDS they have other specialist care needs and their rheumatologist will seek the help of an appropriate specialist but most patients with EDS do not need to see multiple specialists.

The paediatric and adult rheumatologists currently working in Ireland are trained in the management of EDS as are the other specialists who are involved in EDS care pertinent to their own specialty area.

I trust this answers your question to your satisfaction.

Yours sincerely,



Emma Benton

General Manager

Acute Operations