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**Date: 07/06/2019**

Deputy Thomas Broughan TD

Dáil Éireann

Leinster House

Dublin 2

**PQ No. 22976/19** To ask the Minister for Health the steps he is taking to address the needs of persons with Ehlers-Danlos syndrome and hypermobility spectrum disorders; his plans to improve services for persons with the conditions in 2019 and 2020; and if he will make a statement on the matter.

Dear Deputy Broughan,

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.

As it is a rare condition the diagnosis of EDS is usually dependent on access to a specialist consultant such as a paediatric rheumatologist for children and an adult rheumatologist for adults. Treatment of hypermobility largely consists of education, counselling, physiotherapy, occupational therapy, and pain management including psychology, all of which are available through the HSE.

The Model of Care for Rheumatology in Ireland was produced by the National Clinical Programme for Rheumatology in 2018 and identifies that an increase in consultant rheumatologist posts is necessary to provide required access to services, and manage the adult waiting lists. While we have sufficient trainees who are qualified no additional funding has been granted for new consultant posts in Rheumatology.

Within paediatrics, an additional paediatric consultant rheumatologist, and multidisciplinary team, has recently been allocated to address the paediatric waiting list.

Ireland does not require a single specialist in EDS as paediatric and adult rheumatologists are trained in the diagnosis and management of EDS and it is the position of the NCPR that we should continue to increase access to paediatric and adult rheumatology services for all the people of Ireland based on equitable triage of the severity of their condition.

I trust this answers your question to your satisfaction.

Yours sincerely,



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**Emma Benton**  
**General Manager**  
**Acute Operations**