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Deputy Thomas Broughan TD

Dáil Éireann

Leinster House

Dublin 2

PQ No. 22975/19 To ask the Minister for Health if he will seek funding in Budget 2020 to provide resources for the establishment of a dedicated department at a university hospital here to treat persons with Ehlers-Danlos syndrome and hypermobility spectrum disorders to be led by a specialist consultant on the conditions; 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 Ehlers Danlos Syndrome 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.

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

The National Clinical Programme for Rheumatology produced a Model of Care for Rheumatology Services in 2018 which identifies that an increase in consultant rheumatologist posts is required to manage the adult waiting list which is currently averaging over 2 years nationally. Funding for new consultants have not been

forthcoming whilst we have sufficient trainees who are qualified and ready to take up consultant posts.

The NCPR does not agree that Ireland requires a single specialist in EDS as paediatric and adult rheumatologists are trained in the diagnosis and management of EDS and it is the position 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,



Emma Benton

General Manager

Acute Operations