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Deputy Holly Cairns TD

Dáil Éireann

Leinster House

Dublin 2

PQ No. 2599/22

To ask the Minister for Health the steps he is taking to provide medical treatment for persons diagnosed with Ehlers Danlos syndrome; and if he will make a statement on the matter.

Dear Deputy Cairns,

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:

The National Clinical Programme for Rheumatology (NCPR) are active in the management of Ehlers Danlos syndrome (EDS); a rare disease with various different subtypes and great variability in symptoms and co-morbidities.

The principal clinical manifestation is hypermobility/hyperelasticity of soft tissues particularly joints and therefore the medical discipline of rheumatology provides a role in the diagnosis and management of patients with EDS when they have joint symptoms.

EDS patients suffer from hypermobile joints and skin and in most patients they have only mild or moderate symptoms which include joint pain and poor skin wound healing. These patients are managed mainly within primary care services by their GP and physiotherapy once the diagnosis is confirmed. As it is a rare disease, diagnosis of less severe cases may unfortunately be delayed as a GP would only very rarely encounter a patient with EDS during their career.

Where patients have severe EDS of the joints or where they have other specialist care needs they are referred to an appropriate hospital specialist but most patients with EDS do not need to see multiple specialists. EDS is managed by a number of different specialties which is the standard practice internationally. The consultants in the relevant specialties we have in Ireland are trained in the diagnosis and management of EDS. The paediatric and adult rheumatologists currently working in Ireland are trained in the diagnosis and management of the various forms of EDS and patients with severe joint symptoms are referred to rheumatology services.

As EDS is an inherited disease, the most severe forms of EDS usually present first in childhood and care of these patients by multiple specialists is provided at Children's Health Ireland (CHI) at Crumlin. Multidisciplinary specialty care for EDS is available through the relevant specialties of cardiology, neurology, rheumatology, gastroenterology, orthopaedics and physiotherapy at the paediatric services at CHI at Crumlin and through neurosurgery at CHI at Temple Street.

Hypermobililty EDS (HM EDS) previously known as type 3, often poses the biggest diagnostic dilemma and uncertainty for parents as there is no genetic test available to confirm the diagnosis. Symptoms and signs can vary greatly from patient to patient but in particular this group appear to be at greatest risk from overlapping chronic pain syndromes. It remains a clinical diagnosis so is dependent on the clinician's assessment and opinion although with recent update in International diagnostic criteria (2017) this is becoming less of an issue.

The NCPR advises that the needs of persons with EDS, and all rheumatology patients of similar needs, will be most appropriately addressed by seeking the phased full implementation of the Rheumatology Model of Care. This would provide enhanced access to appropriate specialist multidisciplinary rheumatology care, as patients with EDS transition their care to adult rheumatology services. This requires expansion of rheumatology services nationally with an increase of current consultant rheumatologist numbers over the next 10 years.

I trust this answers your question to your satisfaction.

Yours sincerely,

Emma Benton

General Manager

Acute Operations