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Date: 15/11/2019

Deputy Noel Rock TD
Dáil Éireann
Leinster House
Dublin 2

PQ No. 44793/19, 44794/19, 44795/19

- **To ask the Minister for Health the person or body within the HSE rheumatology model of care document that has expertise in treating patients with Ehlers-Danlos syndrome; and if he will make a statement on the matter.**
- **To ask the Minister for Health the specific pathways for Ehlers-Danlos syndrome patients; and if he will make a statement on the matter.**
- **To ask the Minister for Health the person or body that has the expertise to coordinate the other relevant consultant specialists needed for the care of persons with Ehlers-Danlos syndrome; and if he will make a statement on the matter.**

Dear Deputy Rock,

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

Response:

The Model of Care for Rheumatology recommends minimal staffing standards, based on population, for each rheumatology department in order to provide appropriate treatment to all patients with rheumatological diseases. This model aims to ensure that all rheumatology patients are seen, assessed and treated by the right person, in the right place and in the timeliest manner. Paediatric and adult rheumatologists currently working within the state are trained in the management of Ehlers Danlos syndrome (EDS) as are the other specialists who are involved in EDS care.

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 who suffer from hypermobile joints and skin are managed largely within primary care services once the diagnosis is confirmed.

As it is an inherited disease the most severe forms of EDS usually presents first in childhood, care of these patients by multiple specialists is co-ordinated by the paediatric rheumatologists at Our Lady's Children's Hospital (OLHC) in Crumlin. The Rheumatology Model of Care does not propose a single multidisciplinary clinic solely for EDS. The National Clinical Programme for Rheumatology (NCPR)

has sought an increase in rheumatology staffing for all patients with a third consultant due to be recruited and appointed at OLHC and 2 advanced nurse practitioners already appointed. This additional staffing provides improved means to co-ordinate multidisciplinary care for EDS.

Where patients have severe EDS they may have other specialist care needs for which their rheumatologist will seek the expertise of an appropriate specialist. Existing multidisciplinary specialty care for EDS is available through the specialties of cardiology, neurology, rheumatology, gastroenterology, orthopaedics and physiotherapy at the paediatric services at Our Lady Hospital Crumlin (OLHC) and through neurosurgery at Temple Street Children's Hospital. The NCPR acknowledges the challenges for EDS patients seeking access to rheumatology and other specialist services. These issues are multifactorial for the small group of patients with rare but serious EDS who need to see multiple specialists. Most patients with EDS do not need to see multiple specialists.

As patients with EDS transition their care to adult rheumatology services they require timely access to these services. 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 in order to provide appropriate specialist multidisciplinary rheumatology care to all persons with rheumatological diseases in Ireland.

I trust this answers your question to your satisfaction.

Yours sincerely,



Emma Benton

General Manager

Acute Operations