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Deputy Colm Burke TD

Dáil Éireann

Leinster House

Dublin 2

PQ No. 21361/22, PQ 21358/22, PQ 21359/22

PQ No. 21361/22 - To ask the Minister for Health the location that his Department provides information on Huntington's disease including the care and services that persons may need or be entitled to following diagnosis; and if he will make a statement on the matter.

PQ 21358/22 - To ask the Minister for Health the number of patients being seen at Huntington's disease weekly clinics; the way that multi-disciplinary care is provided for these patients; the medical disciplines from which staff at these clinics are drawn; and if he will make a statement on the matter.

PQ 21359/22 - To ask the Minister for Health his plans to ensure Huntington's disease patients are provided with diagnostic pathways and follow-up pathways after diagnosis to help them understand their journey from first presenting symptoms to planning care from after diagnosis; his plans to provide patients with a named medical professional or medical team responsible for coordination of care following diagnosis considering the complex and multi-disciplinary nature of the disease; and if he will make a statement on the matter.

Dear Deputy Burke,

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:

Huntington Disease is a rare and complex hereditary neurological condition with an estimated 1,000 persons suffering from the disease in Ireland.

In response to the PQ's, the National Clinical Programme for Neurology would like to advise, that initial stakeholder meetings in collaboration with the Scheduled Care Transformation Programme in relation to the development of a Huntington Disease Pathway in the republic of Ireland have commenced.

As Huntington Disease is a complex condition requiring support across all aspects of the healthcare ecosystem including the voluntary sector, further development of a pathway specific to the needs of those with Huntington disease will require significant engagement with a broad spectrum of stakeholders. The development of a Huntington Disease pathway will support the development of a service specific to the needs of the HD population in Ireland. Additional engagement and extensive consultation between the Scheduled Care Transformation Group, the National Clinical Programme for Neurology, representatives from Psychiatry; Mental Health, Dementia, Genetics; Palliative Care, Psychology, community services and the Huntington Disease Ireland Voluntary Organisation, to map out the broad range of service needs that a Huntington Disease patient requires is currently being planned and it is envisaged that a broader stakeholder meeting will be held in the coming months.

A weekly clinic for HD patients has been initiated in Beaumont Hospital, Dublin. The objective is to share best practice and mirror existing successful National Motor Neuron Disease (MND) service in providing multi-disciplinary care and outreach services. Through the 2022 HSE's estimates process, funding will be requested to support the development of this HD clinic, as resources are currently limited. This will form part of a planned five-year incremental development of a HD service for Ireland, in keeping with the objectives of Sláintecare.

I trust this answers your question to your satisfaction.

Yours sincerely,



Emma Benton

General Manager

Acute Operations