



Géaroibríochtaí
Aonad 4A, Áras Dargan, An Ceantar Theas, An Bóthar
Míleata Cill Mhaighneann, Baile Átha Cliath 8

Acute Operations
Unit 4A, The Dargan Building, Heuston South Quarter,
Military Road, Kilmainham, Dublin 8

☎: 0179 59971 📧: acute.operations@hse.ie

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Deputy David Cullinane TD
Dáil Éireann
Leinster House
Dublin 2

PQ 19211/22

To ask the Minister for Health if there are plans to establish a diagnostic and aftercare pathway for persons with Huntington's disease; his plans to recruit coordinated a multi-disciplinary team to provide symptom management, care planning and anticipatory care; and if he will make a statement on the matter

Dear Deputy Cullinane,

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's Disease is a rare and complex hereditary neurological condition with an estimated 1,000 persons suffering from the disease in Ireland. The National Clinical Programme for Neurology (NCPN) have been working in conjunction with HSE Scheduled Care Transformation Programme (SCTP), Strategy and Planning, throughout 2021/2022 on proposed development of an integrated pathway for Huntington's Disease.

As Huntington's Disease is a complex condition that requires support across all aspects of the healthcare ecosystem including the voluntary sector, development of an integrated pathway will require detailed engagement with all stakeholders. There is no dedicated national service for Huntington's Disease (HD) at present, although patients are seen regularly through the ENROL-HD research programme at Beaumont Hospital. The ENROL HD Centre at Beaumont hospital already participates in the

development of international guidelines for Huntington's Disease and has laid the groundwork for the provision of multidisciplinary care to HD patients in Ireland.

A weekly clinic for HD patients has also been initiated in Beaumont, with limited administrative support. The objective of this clinic is to share best practice and mirror the existing successful national Motor Neuron Disease (MND) service in providing multidisciplinary care.

I trust this answers your question to your satisfaction.

Yours sincerely,



Emma Benton

General Manager

Acute Operations