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Deputy Colm Burke, TD
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

RE: PQ 12511/22

To ask the Minister for Health if consideration will be given to the development of a new work stream within the current National Clinical Programme for Neurology to establish the details of a model of care for Huntington's disease affected families in Ireland that would fit within the Sláintecare Implementation Strategy and Action Plan; 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 relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Programme for Neurology (NCPN) on your question and have been informed that the following outlines the position.

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 system, 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.

NCPN is currently developing a business case to support a five-year incremental development of a Huntington's Disease service, in keeping with the objectives of Sláintecare.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely



Anne Horgan
General Manager