

Dearadh agus Nuálaíocht Chliniciúil; Oifig an Príohoifigeach Cliniciúil Ospidéal Dr. Steevens, D08 W2A8 R: clinicaldesign@hse.ie

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Deputy Sorca Clarke, TD Dáil Éireann Leinster House Kildare Street Dublin 2

RE: PQ 29008/22

To ask the Minister for Health when a specialist multiple system atrophy nurse will be provided for those diagnosed with this progressive neurologic disease; the number of persons with this diagnosis; and the current access to specialist multiple system atrophy care.

Dear Deputy Clarke,

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.

Multiple system atrophy (MSA) is a rare condition of the nervous system that causes gradual damage to nerve cells in the brain. This can impact a patient's balance, movement and the autonomic nervous system (which controls breathing, digestion and bladder control). In Ireland, patients with MSA are referred to neurological services. Currently, in Ireland, there is no disease registry for this rare disorder and thus numbers living with the disease are unknown. MSA would have a similar prevalence to Motor Neuron Disease (MND) based on international data. This would suggest that approximately up to 250 patients in Ireland have MSA, with up to 80 patients being diagnosed yearly.

Patients being assessed for or diagnosed with MSA usually attend Parkinson Disease and other Movement Disorder Clinics at some of the level 4 hospitals around the country, such as Mater Misericordiae University Hospital; Beaumont Hospital; St Vincent's University Hospital; Tallaght University Hospital; St James Hospital; University Hospital Limerick; Cork University Hospital; Galway University Hospital and so forth.

St Vincent's University Hospital runs a dedicated MSA Clinic. Additionally, Tallaght University Hospital has recently been appointed ERN (European Reference Network) centre of expertise for Atypical Parkinsonism and a condition-specific clinic is run quarterly for MSA, Progressive Supranuclear Palsy (PSP) and Corticobasal Syndrome (CBS).

NCP Neurology, in collaboration with Neurologists working around the country, are exploring the development of specialised hubs or centres in the diagnosis and management of complex Atypical Parkinsonism cases (including MSA) that require the input of a specialised multi-disciplinary team.



Having a dedicated team, including a specialist multiple system atrophy nurse, would provide a holistic and specialised service and also allow for international collaboration in research and trials as appropriate.

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

